ADULT SERVICES COMMITTEE

AGENDA

Thursday 12 July 2018

at 10.00am

in Committee Room B,
Civic Centre, Hartlepool

MEMBERS: ADULT SERVICES COMMITTEE

Councillors Hamilton, Little, McLaughlin, C Richardson, Tennant, Thomas and 1 vacancy.

1. APOLOGIES FOR ABSENCE

2. TO RECEIVE ANY DECLARATIONS OF INTEREST BY MEMBERS

3. MINUTES

3.1 To receive the Minutes and Decision Record in respect of the meeting held on 14 June 2018 *(for information as previously circulated)*.

4. BUDGET AND POLICY FRAMEWORK ITEMS

No items.

5. KEY DECISIONS

No items.

6. OTHER ITEMS REQUIRING DECISION

6.1 Motor Neurone Disease - The MND Charter (*Director of Adult & Community Based Services)*

7. ITEMS FOR INFORMATION

7.1 Access To Transport For People With A Disability (*Director of Adult and Community Based Services*

7.2 Care Quality Commission Report: Driving Improvement *(Director of Adult & Community Based Services)*

8. ANY OTHER BUSINESS WHICH THE CHAIR CONSIDERS URGENT

FOR INFORMATION

Date of next meeting – Thursday 6 September 2018 at 10.00am in the Civic Centre, Hartlepool.

ADULT SERVICES COMMITTEE

MINUTES AND DECISION RECORD

14 June 2018

The meeting commenced at 10.00 am in the Civic Centre, Hartlepool

Present:

Councillor: Stephen Thomas (In the Chair)

Councillors: Lesley Hamilton, Sue Little, Mike McLaughlin, John Tennant and Carl Richardson

Also present:
Judy Gray, Zoe Sherry and Gordon and Stella Johnston - Healthwatch

Officers: Jill Harrison, Director of Adult and Community Based Services
Angela Armstrong, Principal Democratic Services Officer

1. Welcome to the Committee

The Chair welcomed everyone to the first meeting in the municipal year, in particular the new Members of the Committee Councillors Sue Little and John Tennant.

2. Apologies for Absence

Apologies for absence were received from Frank Harrison – 50+ Forum.

3. Declarations of Interest

Councillor Stephen Thomas declared his usual personal interest as an employee of Healthwatch along with a prejudicial interest in minute 6 and indicated he would leave the meeting during the consideration of that item. Councillor Carl Richardson declared a personal interest in minute 5.

It was noted that in order to comply with the recently introduced General Data Protection Regulations (GDPR), members of the public who attend Council meetings will not be recorded in the attendance of the minutes. Only attendees who were attending on behalf of an organisation will be included.

4. Minutes of the meeting held on 29 March 2018

Received.

The Director of Adult and Community Based Services provided the Committee with the following updates from the minutes of the meeting held on 29 March 2018:

Adult Carers Support – It was highlighted that it was Carers' Week and there had been a full programme of events all week. It was concluding on Friday 15 June with a carnival themed event at Hartlepool's Maritime Experience which would include market stalls, the opportunity to have a taster session in relaxation, salsa dancing and many other activities. The day would finish with a consultation meeting from 2.15pm to 3.15pm in relation to updating Hartlepool's Carers' Strategy and everyone was welcome to attend. In addition, it was noted that there was a Hartlepool Carers' awards event on the evening to recognise the contribution of carers within Hartlepool.

Support for Adult Carers in Hartlepool – It was noted that the tendering process for the support for adult and young carers had recently been completed and the contract had been awarded to Hartlepool Carers. Officers would continue to work with them to further develop support for carers within Hartlepool. The Chair indicated he was very proud to work closely with Hartlepool Carers to support the community of carers in Hartlepool who do a tremendous amount of unpaid work caring for people.

5. Update: Care Homes for Older People (*Director of Adult and Community Based Services*)

Type of decision

For information.

Purpose of report

To provide the Adult Services Committee with an update in relation to care home provision for older people.

Issue(s) for consideration

The Committee receives regular updates in relation to CQC inspection ratings, vacancy data and progress made in a number of areas. Since the last update report there had been a number of developments a summary of which follows:

CQC Ratings – Since the last meeting, two homes rated as 'requires improvement' had been re-inspected and were now rated as 'good' which reflected a further improvement in the overall position for care homes for older people.

Outstanding Rating – The CQC inspection report from the inspection of

Sheraton Court was published in April 2018 and confirmed that it was awarded a rating of ‘outstanding’ for the caring domain, within an overall ‘good’ rating.

Quality Standards Framework (QSF) – Since the last meeting, Officers had worked closely with providers, managers and staff to implement action plans that deliver improvements, in conjunction with gathering evidence for the next round of ratings. The new QSF grades were attached and indicated that no homes were rated below Grade 2.

De Bruce Court Care Home – The home has been open for residents since February 2018 and was officially opened on 21 March by the Chair of this Committee. The provider was working with the Council to manage admissions in the initial months of operating; an approach that had been very successful with other new provision.

Support provided to the Care Home Market – A workshop for Care Home Managers and Activities Co-ordinators was held on 17 April 2018 and was attended by over 30 care home staff. Feedback from the event was extremely positive.

CCG/HBC Training and Education Programme – The North Tees and Hartlepool Education Alliance was progressing with a training programme being implemented. Attendance was particularly good in Hartlepool with 100% of care homes participating in some elements of the training. Better Care Fund resources were recently approved to continue funding the programme for a further two years.

Care Homes Fees – Care home fees were increased by an additional 3.4% in 2017/18 linked to the Improved Better Care Fund and this uplift was backdated to April 2017. The fee uplift offered to providers in 2018/19 was 3.66%. Providers continue to express concerns about financial pressures along with the increasing complexity of individuals requiring care which were expressed equally by residential care providers.

A Member sought clarification on the financial constraints currently faced by care homes and the Director of Adult and Community Based Services commented that recruitment and retention of nurses was a particular challenge for care home providers as they were unable to compete with NHS terms and conditions. In addition to this, care homes had raised issues regarding the increasingly complex needs of their residents. In response to a question from a Member, the Director of Adult and Community Based Services commented that the local authority had arrangements in place should a care home suffer from financial difficulties or cease to operate to ensure that residents and families were supported throughout the process.

The provision of equipment was referred to and the Director of Adult and Community Based Services responded that this service was commissioned by the Tees Local Authorities and NHS partners and was provided by the Tees Community Equipment Service which offered the vast majority of the equipment needed.

A discussion ensued on CQC ratings of the care homes and the positive news that two care homes previously rated as ‘requires improvement’ were now rated as ‘good’, with another care home achieving an ‘outstanding’ rating for the level of care provided. This was a tremendous success and everyone involved should be very proud. However, the Chair commented that continuous improvement with the best possible care provision was strived for with the aim of all homes being rated at least ‘good’ in what was a very volatile market where things could change very quickly.

The Chair referred to the challenges faced by care homes in relation to the recruitment and retention of nurses and added that this was one of the reasons that the Council was exploring opportunities to develop a Care Academy within Hartlepool which would promote care as a profession and support career progression. It was noted that a report would be submitted to the Committee at a later date with an update on the establishment of a Care Academy.

In conclusion, the Chair highlighted that regular updates on care home provision within Hartlepool would be submitted to Committee and on behalf of the Committee, thanks were conveyed to care home providers and managers and Officers who work with care homes for their tireless efforts in improving care provision within Hartlepool.

The Director of Adult and Community Based Services responded to a number of questions raised by members of the public.

Decision

The report was noted.

In view of Councillor Stephen Thomas’ earlier declaration of a prejudicial interest, he left the meeting and Councillor Mike McLoughlin took the Chair.

6. Healthwatch Hartlepool Enter and View Reports

(*Healthwatch Hartlepool)*

Type of decision

For information.

Purpose of report

To inform the Adult Services Committee of the outcomes of the recent Enter and View visits conducted by Healthwatch Hartlepool to Charlotte Grange and Queens Meadow care homes.

Issue(s) for consideration

It was reported that Healthwatch Hartlepool had undertaken unannounced visits to Charlotte Grange on 9 November 2017 and Queen's Meadow Care Home on 29 January 2018. The detailed reports were attached and representatives from Healthwatch presented a summary of issues identified and recommendations made.

A lengthy discussion took place on the level of care provided, which included staffing levels, sharing of good practice and the need for care to be tailored to the needs of each individual resident. In addition, concern was expressed by Members at the lack of response to the Healthwatch inspection reports from care home managers, despite this being requested. The Director of Adult and Community Based Services advised that observations and recommendations from the inspection reports were considered by Officers and, where necessary, added to action plans and monitored as part of regular monitoring programmes. The Director of Adult and Community Based Services indicated that a letter could be sent to care home managers regarding the lack of feedback to Healthwatch as a result of their inspection reports.

The Chair thanked the Healthwatch representatives who were volunteers, for their detailed and comprehensive inspection and subsequent report which was valued by the Committee and confirmed an expectation that care home managers should provide feedback to Healthwatch within the prescribed 20 days following receipt of a report.

Decision

(1) The reports were noted.
(2) That the Director of Adult and Community Based Services write to all care home managers on behalf of the Committee outlining the concerns of Members at the lack of feedback on the Healthwatch inspection reports. This letter will be shared with Committee members.

Councillor Stephen Thomas in the Chair.

7. Any Other Items which the Chairman Considers are Urgent

The Chairman ruled that the following items of business should be considered by the Committee as a matter of urgency in accordance with the provisions of Section 100(B) (4)(b) of the Local Government Act 1972 in order that the matter could be dealt with without delay.

Minute 8 – Healthwatch Inspections

Minute 9 – Tees Esk and Wear Valley NHS Trust – CQC Inspection

8. Any Other Business - Healthwatch Inspections

The Chair thanked the volunteer Healthwatch representatives for undertaking such comprehensive inspections and compiling detailed inspection reports in such a professional and efficient manner. He added that the reports should be viewed as a real asset to the care homes which should assist the managers to prepare and plan for future CQC inspections and it was only right and proper that these inspection reports were responded to.

9. Any Other Business – Tees, Esk and Wear Valley NHS Trust

A representative from Healthwatch informed the Committee that the Tees, Esk and Wear Valley NHS Trust were currently subject to a Care Quality Commission around community services. The outcome of that inspection would be provided to the Committee at a future meeting.

The meeting concluded at 11.35 am

H MARTIN

INTERIM CHIEF SOLICITOR

PUBLICATION DATE: 21 June 2018

ADULT SERVICES COMMITTEE

12 July 2018

HARTLEPOOL
BOROUGH COUNCIL

Report of: Director of Adult & Community Based Services

Subject: MOTOR NEURONE DISEASE - THE MND CHARTER

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1. TYPE OF DECISION/APPLICABLE CATEGORY

1.1 Non key decision.

2. PURPOSE OF REPORT

2.1 To seek approval from the Adult Services Committee to adopt the Motor Neurone Disease Charter and to refer the Charter to the Health & Wellbeing Board for consideration by partners.

3. BACKGROUND

3.1 Motor Neurone Disease (MND) is a fatal, rapidly progressing disease that affects the brain and spinal cord. It can leave people locked in a failing body, unable to move, talk and eventually breathe. A person's lifetime risk of developing MND is up to 1 in 300. It kills around 30% of people within 12 months of diagnosis and more than 50% within two years. It affects people from all communities and has no cure.

3.2 MND affects up to 5,000 adults in the UK at any time. Statistics suggest that six people are diagnosed every day and six people die each day.

3.3 Assuming an equitable distribution of MND across the country, the national statistics equate to 5 people in Hartlepool living with the condition at any time.

4. MOTOR NEURONE DISEASE ASSOCIATION (MNDA)

4.1 The MND Association is the only national charity in England, Wales and Northern Ireland focused on MND care, research and campaigning. The organisation funds 20 care centres and networks in partnership with NHS Trusts.

4.2 The MND Association employs 26 Regional Care Development Advisors who are in touch with people living with MND and work to influence local health and social care service providers.

5. THE MND CHARTER

5.1 The MND Charter is a statement of the respect, care and support that people living with MND and their carers deserve, and should expect. The charter recommends that everyone with a connection to MND (either personally or professionally) should recognise and respect the rights of people with MND as set out in the Charter, and work towards the Charter's vision of the right care, in the right place at the right time.

5.2 The MND charter focuses on 5 key statements relating to:

- the right to an early diagnosis;
- the right to high quality care and treatments;
- the right to be treated as individuals and with dignity and respect;
- the right to maximise quality of life; and
- the rights of carers of people with MND.

5.3 Further detail is included in the Charter document (attached as **Appendix 1**).

6. PARTNERSHIP WORKING & NEXT STEPS

6.1 Integral to the success of the Charter is the relationship between health, social care, housing and adaptations, carers' services and transport.

6.2 In line with the requirements of the Charter, a named MND Social Worker has been identified who will act as the appointed lead to improve early referral to Adult Services within the Council. In the short time since being appointed to this role, the named Social Worker for MND has made contact with the local MND Nurse Specialist and identified some positive ways that relationships can be developed for the future. This includes attendance at an Annual Conference in November, involvement in quarterly meetings where individuals with MND are reviewed and an introduction to the weekly MND clinic that operates from James Cook University Hospital. Information has also been accessed about support available from The MND Association and The National MND Association, which can include grants to meet the costs of adaptations, for example. Information and resources relating to MND will be made available via Hartlepool Now (www.hartlepoolnow.co.uk) as well as being included in the Adults Practice Manual which is currently being developed as a resource for Council staff.

6.3 If the Charter is adopted, Adult Services will also engage with Hartlepool & Stockton on Tees Clinical Commissioning Group to develop an action plan linked to MND assessment and management, in line with the National Institute of Clinical Excellence (NICE) Guidance which was issued in February 2016, and is attached as **Appendix 2**.

7. RISK IMPLICATIONS

7.1 There are no risk implications associated with this report.

8. FINANCIAL CONSIDERATIONS

8.1 There are no financial consideration associated with this report. A named MND Social Worker will be identified from within existing resources.

9. LEGAL CONSIDERATIONS

9.1 There are no legal considerations associated with this report.

10. CHILD AND FAMILY POVERTY

10.1 No child and family poverty considerations have been identified.

11. EQUALITY AND DIVERSITY CONSIDERATIONS

11.1 The MND Charter aims to support people with MND and ensure people are treated equitably and as individuals, with dignity and respect.

12. STAFF CONSIDERATIONS

12.1 There are no staffing considerations associated with this report. An existing member of staff will be identified to undertake the role of named MND Social Worker and will be offered appropriate training if required.

13. ASSET MANAGEMENT CONSIDERATIONS

13.1 There are no asset management considerations associated with this issue.

14. RECOMMENDATIONS

14.1 It is recommended that the Adult Services Committee support the adoption of the MND Charter and refer the Charter to the Health and Wellbeing Board for consideration by partners.

15. REASONS FOR RECOMMENDATIONS

15.1 Adoption of the Charter demonstrates recognition of the respect, care and support that people living with MND and their carers deserve. A referral to the

Health and Wellbeing Board will recognise that this agenda has an impact across all agencies, and enable the issue to be considered on a broader basis by partners who work with residents of Hartlepool.

16. CONTACT OFFICER

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6.1 Appendix 1

mnda
motor neurone disease
association

CHAMPION
THE CHARTER
ON YOUR
DOORSTEP

themndcharter

Achieving quality of life, dignity and respect for people with MND and their carers

The MND Charter is a statement of the respect, care and support that people living with motor neurone disease (MND) and their carers deserve, and should expect.

We believe that everyone with a connection to MND, either personally or professionally, should recognise and respect the rights of people with MND as set out in the Charter, and work towards the Charter's vision of the right care, in the right place at the right time.

About MND:

- MND is a fatal, rapidly progressing disease that affects the brain and spinal cord.
- It can leave people locked in a failing body, unable to move, talk and eventually breathe.
- A person's lifetime risk of developing MND is up to one in 300.
- It kills around 30% of people within 12 months of diagnosis, more than 50% within two years.
- It affects people from all communities.
- It has no cure.

Therefore, what matters most is that people with MND receive a rapid response to their needs and good quality care and support, ensuring the highest quality of life as possible and the ability to die with dignity. The MND Charter serves as a tool to help make this happen.

MND is a devastating, complex disease and particularly difficult to manage. We believe that if we get care right for MND we can get it right for other neurological conditions, and save public services money in the long run. But more importantly, we can make a positive difference to the lives of people with MND, their carers and their loved ones.

1

People with MND have the right to an early diagnosis and information

THIS MEANS:

- An early referral to a neurologist.
- An accurate and early diagnosis, given sensitively.
- Timely and appropriate access to information at all stages of their condition.

There is no diagnostic test for MND – it can only be diagnosed by ruling out other neurological conditions. People with MND can be halfway through their illness before they receive a firm diagnosis.

GPs need to be able to identify the symptoms and signs of a neurological problem and refer directly to a neurologist in order to speed up diagnosis times for MND.

Appropriate tests must be carried out as soon as possible to confirm MND. The diagnosis should be given by a consultant neurologist with knowledge and experience of treating people with MND[1]. The diagnosis should be given sensitively, in private, with the person with MND accompanied by a family member/friend and with time to ask questions. A follow-up appointment with the neurologist should be arranged soon after diagnosis.

At diagnosis people with MND should be offered access to appropriate information and should be informed about the MND Association. Appropriate information should be available at all stages of the person's condition in a language of their choice.

2

People with MND have the right to high quality care and treatments

THIS MEANS:

- Access to co-ordinated multidisciplinary care managed by a specialist key worker with experience of MND.
- Early access to specialist palliative care in a setting of their choice, including equitable access to hospices.
- Access to appropriate respiratory and nutritional management and support, as close to home as possible.
- Access to the drug riluzole.
- Timely access to NHS continuing healthcare when needed.
- Early referral to social care services.
- Referral for cognitive assessment, where appropriate.

People with MND may need care provided by health and social care professionals from up to 20 disciplines. This clearly needs co-ordination to work effectively. Co-ordinated care can improve the quality of life of people with MND and provide value for money for the NHS by preventing crises and emergency hospital admissions. The care should be co-ordinated by a specialist key worker with experience of MND who can anticipate needs and ensure they are met on time. Ongoing education for health and social care professionals is important to reflect advances in healthcare techniques and changes in best practice.

A third of people with MND die within 12 months of diagnosis. Early access to specialist palliative care[2] soon after diagnosis is therefore vital and should be available in a setting of the person's choice. Some hospices give preferential access to people with a cancer diagnosis. It is important that access is based on need, not diagnosis, so that people with MND have equitable access to hospice care. Hospices can provide high-quality respite care, which can benefit both the person with MND and their carer.

As MND progresses, the respiratory muscles and muscles of the mouth and throat may be affected. People with MND may therefore need respiratory and nutritional support. It is important that these services are available as close to the person's home as possible so that travelling is minimised and support is available quickly.

In 2001 the National Institute for Health and Care Excellence (NICE) recommended riluzole as a cost-effective drug for people with MND. GPs can be reluctant to prescribe riluzole on cost grounds, despite its NICE-approved status, or to monitor for side effects during its use. However, it is vital that people with MND have ongoing access to this important treatment.

As the disease progresses, people with MND may need more intensive health care. It is important that people with MND have timely access to NHS continuing healthcare when they need it.

People with MND are likely to need help with getting up, washing, dressing and preparing food as the disease progresses. Access to social care services is therefore important to maintain quality of life. People with MND may also need access to cognitive assessment, as up to half of people with the disease experience changes in cognition.

3

People with MND have the right to be treated as individuals and with dignity and respect

THIS MEANS:

- Being offered a personal care plan to specify what care and support they need.
- Being offered the opportunity to develop an Advance Care Plan to ensure their wishes are met, and appropriate end-of-life care is provided in their chosen setting.
- Getting support to help them make the right choices to meet their needs when using personalised care options.
- Prompt access to appropriate communication support and aids.
- Opportunities to be involved in research if they so wish.

Everyone with MND should be offered a personal care plan[3] to specify what care and support they need. The plan should be regularly reviewed as the disease progresses and the person's needs change.

People with MND should be offered the opportunity to develop an Advance Care Plan[4] to make clear their wishes for future care and support, including any care they do not wish to receive. The plan should be developed with support from a professional with specialist experience and may include preferences for end-of-life care.

Some people with MND will need support to help them make the right choices to meet their needs when using personalised care options, such as personal budgets.

As the disease progresses, some people with MND will experience difficulty speaking. It is important that people with MND can access speech and language therapy to help them maintain their voice for as long as possible. However, as the disease progresses, people with MND may need access to communication aids including augmentative and alternative communication (AAC)[5]. The ability to communicate is a basic human right. For people with MND, communication support and equipment are vital in order to remain socially active and to communicate their wishes about their care, especially during hospital stays and other medical environments.

Many people with MND value the opportunity to be involved in research as it provides hope that one day an effective treatment will be developed. Everyone with MND who wishes to should be able to participate in research as far as is practicable.

4

People with MND have the right to maximise their quality of life

THIS MEANS:
- Timely and appropriate access to equipment, home adaptations, environmental controls, wheelchairs, orthotics and suitable housing.
- Timely and appropriate access to disability benefits.

People with MND may find their needs change quickly and in order to maximise their quality of life, they may need rapid access to equipment, home adaptations, wheelchairs and suitable housing. These needs should be anticipated so that they are met in a timely way. This is particularly true of wheelchairs which are important for maximising independence and quality of life.

People with MND need timely and appropriate access to disability benefits to help meet the extra costs of living with a disability. Information on appropriate benefits needs to be readily accessible in one place and easily understandable.

5

Carers of people with MND have the right to be valued, respected, listened to and well supported

THIS MEANS:
- Timely and appropriate access to respite care, information, counselling and bereavement services.
- Advising carers that they have a legal right to a Carer's Assessment of their needs[1], ensuring their health and emotional well being is recognised and appropriate support is provided.
- Timely and appropriate access to benefits and entitlements for carers.

Caring for someone with MND is physically and emotionally demanding. Carers need to be supported in order to maintain their caring role. Every carer should have their needs assessed and given timely and appropriate access to respite care, information, counselling and bereavement services. It is important to support the emotional and physical needs of the carer in a timely way so that they can continue their caring role.

Carers should also have timely and appropriate access to benefits and entitlements to help manage the financial impact of their caring role.

[1] Recomendation in the NICE guideline on MND.

[2] Specialist palliative care – palliative care is the active holistic care of patients with progressive illness, including the provision of psychological, social and spiritual support. The aim is to provide the highest quality of life possible for patients and their families. Specialist palliative care is care provided by a specialist multidisciplinary palliative care team.

[3] Personal care plan – a plan which sets out the care and treatment necessary to meet a person's needs, preferences and goals of care.

[4] Advance care plan – a plan which anticipates how a person's condition may affect them in the future and, if they wish, set on record choices about their care and treatment and/or an advance decision to refuse a treatment in specific circumstances so that these can be referred to by those responsible for their care or treatment (whether professional staff or family carers) in the event that they lose capacity to decide or communicate their decision when their condition progresses.

[5] Augmentative and Alternative Communication (AAC) – is used to describe the different methods that can be used to help people with speech difficulties communicate with others. These methods can be used as an alternative to speech or to supplement it. AAC may include unaided systems such as signing and gesture as well as aided systems such as low tech picture or letter charts through to complex computer technology.

"Many people with MND die without having the right care, not having a suitable wheelchair, not having the support to communicate.

We have got to set a standard so that people like us are listened to and treated with the respect and dignity we deserve.

We have got to stop the ignorance surrounding this disease and have to make sure that when a patient is first diagnosed with MND, they must have access to good, co-ordinated care and services.

One week waiting for an assessment or a piece of equipment is like a year in most people's lives, because they are an everyday essential to help us live as normal a life as possible and die with dignity"

Liam Dwyer, who is living with MND

For more information:

www.mndassociation.org/mndcharter
Email: campaigns@mndassociation.org
Telephone: 020 7250 8447

We are proud to have the following organisations supporting the MND Charter:

Royal College of General Practitioners
Association of British Neurologists
Royal College of Nursing
Chartered Society of Physiotherapy
College of Occupational Therapists
Royal College of Speech & Language Therapists
British Dietetic Association

MND Association
PO Box 246 Northampton NN1 2PR
www.mndassociation.org

Registered charity no 294354

Motor neurone disease: assessment and management

NICE guideline
Published: 24 February 2016
nice.org.uk/guidance/ng42

Your responsibility

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

Contents

This guideline replaces CG105.

This guideline is the basis of QS126.

Overview

This guideline covers assessing and managing motor neurone disease (MND). It aims to improve care from the time of diagnosis, and covers information and support, organisation of care, managing symptoms and preparing for end of life care.

Who is it for?

- Healthcare professionals and social care practitioners caring for and supporting adults with MND
- Commissioners and providers of MND health and social care services
- Adults with MND, their families and carers

Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in your care.

Making decisions using NICE guidelines explains how we use words to show the strength of our recommendations, and has information about safeguarding, consent and prescribing medicines (including 'off-label' use).

1.1 *Recognition and referral*

1.1.1 Ensure that robust protocols and pathways are in place to:

- inform healthcare professionals about motor neurone disease (MND) and how it may present
- inform healthcare professionals in all settings about local referral arrangements
- ensure continued and integrated care for people with MND across all care settings. **[new 2016]**

1.1.2 Be aware that MND causes progressive muscular weakness that may first present as isolated and unexplained symptoms. These symptoms may include:

- functional effects of muscle weakness, such as loss of dexterity, falls or trips
- speech or swallowing problems, or tongue fasciculations (this is known as bulbar presentation)
- muscle problems, such as weakness, wasting, twitching, cramps and stiffness
- breathing problems, such as shortness of breath on exertion or respiratory symptoms that are hard to explain
- effects of reduced respiratory function, such as excessive daytime sleepiness, fatigue, early morning headache or shortness of breath when lying down. **[new 2016]**

1.1.3 Be aware that MND may first present with cognitive features, which may include:

- behavioural changes

- emotional lability (not related to dementia)
- frontotemporal dementia. **[new 2016]**

1.1.4 If you suspect MND, refer the person without delay and specify the possible diagnosis in the referral letter. Contact the consultant neurologist directly if you think the person needs to be seen urgently. **[new 2016]**

1.1.5 Provide information and support for people and their family members and/or carers (as appropriate) throughout the diagnostic process, particularly during periods of diagnostic uncertainty or delay. **[new 2016]**

1.2 Information and support at diagnosis

Please also refer to the recommendations in NICE's guideline on patient experience in adult NHS services, which includes recommendations on communication, information and coordination of care.

1.2.1 Information about the diagnosis, prognosis and management of MND should be given by a consultant neurologist with up-to-date knowledge and experience of treating people with MND unless it is clinically necessary to give the diagnosis in an urgent situation. The neurologist should have knowledge and expertise in the following:

- Symptoms of MND.
- Types and possible causes of MND.
- Treatment options.
- How MND may progress (including cognitive and behavioural changes) and how progression may affect the treatments offered.
- Crisis prevention (for example, if there is an acute hospital admission or a breakdown in care arrangements).
- Opportunities for people with MND to be involved in research.
- Likely needs and concerns of people with MND and their family members and/or carers (as appropriate).

- Advance care planning. **[new 2016]**

1.2.2 Ask people about how much information they wish to receive about MND, and about their preferences for involving their family members and/or carers (as appropriate). **[new 2016]**

1.2.3 Ensure people are provided with information about MND and support at diagnosis or when they ask for it. If the person agrees, share the information with their family members and/or carers (as appropriate). Information should be oral and written, and may include the following:

- What MND is.
- Types and possible causes.
- Likely symptoms and how they can be managed.
- How MND may progress.
- Treatment options.
- Where the person's appointments will take place.
- Which healthcare professionals and social care practitioners will undertake the person's care.
- Expected waiting times for consultations, investigations and treatments.
- Local services (including social care and specialist palliative care services) and how to get in touch with them.
- Local support groups, online forums and national charities, and how to get in touch with them.
- Legal rights, including social care support, employment rights and benefits.
- Requirements for disclosure, such as notifying the Driver and Vehicle Licensing Agency (DVLA).
- Opportunities for advance care planning. **[new 2016]**

1.2.4 When MND is diagnosed, provide people with a single point of contact for the specialist MND multidisciplinary team (see section 1.5). Provide information about what to do if there are any concerns between assessments or appointments, during 'out-of-hours' or in an emergency, or if there is a problem with equipment. **[new 2016]**

1.2.5 Offer the person with MND a face-to-face, follow-up appointment with a healthcare professional from the multidisciplinary team, to take place within 4 weeks of diagnosis. **[new 2016]**

1.2.6 When MND is suspected or confirmed, inform the person's GP without delay and provide information about the likely prognosis. **[new 2016]**

1.2.7 Set aside enough time to discuss the person's concerns and questions, which may include the following:

- What will happen to me?
- Are there any treatments available?
- Is there a cure?
- How long will I live?
- What will the impact on my day-to-day life be?
- What will happen next with my healthcare?
- Will my children get MND?
- How do I tell my family and friends?
- How will I die? **[new 2016]**

1.2.8 If the person has any social care needs, refer them to social services for an assessment. Be aware that some people with MND may not have informal care available, and may live alone or care for someone else. **[new 2016]**

1.2.9 Advise carers that they have a legal right to have a Carer's Assessment of their needs; support them with requesting this from their local authority. **[new 2016]**

1.3 Cognitive assessments

Please also refer to the recommendations in NICE's guideline on patient experience in adult NHS services.

1.3.1 Be aware that people with MND and frontotemporal dementia may lack mental capacity. Care should be provided in line with the Mental Capacity Act 2005. **[new 2016]**

1.3.2 At diagnosis, and if there is concern about cognition and behaviour, explore any cognitive or behavioural changes with the person and their family members and/or carers as appropriate. If needed, refer the person for a formal assessment in line with the NICE guideline on dementia. **[new 2016]**

1.3.3 Tailor all discussions to the person's needs, taking into account their communication ability, cognitive status and mental capacity. **[new 2016]**

1.4 Prognostic factors

1.4.1 When planning care take into account the following prognostic factors, which are associated with shorter survival if they are present at diagnosis:

- Speech and swallowing problems (bulbar presentation).
- Weight loss.
- Poor respiratory function.
- Older age.
- Lower Amyotrophic Lateral Sclerosis Functional Rating Scale (ALSFRS or ALSFRS-R) score.
- Shorter time from first developing symptoms to time of diagnosis. **[new 2016]**

1.5 Organisation of care

1.5.1 Provide coordinated care for people with MND, using a clinic-based, specialist MND multidisciplinary team approach. The clinic may be community or hospital based. **[new 2016]**

1.5.2 The multidisciplinary team should:

- include healthcare professionals and social care practitioners with expertise in MND, and staff who see people in their home
- ensure effective communication and coordination between all healthcare professionals and social care practitioners involved in the person's care and their family members and/or carers (as appropriate)
- carry out regular, coordinated assessments at the multidisciplinary team clinic (usually every 2–3 months) to assess people's symptoms and needs
- provide coordinated care for people who cannot attend the clinic, according to the person's needs. **[new 2016]**

1.5.3 The multidisciplinary team should assess, manage and review the following areas, including the person's response to treatment:

- Weight, diet, nutritional intake and fluid intake, feeding and swallowing (see section 1.10).
- Muscle problems, such as weakness, stiffness and cramps (see recommendations 1.8.1–1.8.9 in section 1.8).
- Physical function, including mobility and activities of daily living (see section 1.9).
- Saliva problems, such as drooling of saliva (sialorrhoea) and thick, tenacious saliva (see recommendations 1.8.10–1.8.15 in section 1.8).
- Speech and communication (see section 1.11).
- Cough effectiveness (see section 1.13).
- Respiratory function, respiratory symptoms and non-invasive ventilation (see sections 1.12 and 1.14).
- Pain and other symptoms, such as constipation.
- Cognition and behaviour (see section 1.3).
- Psychological support needs (see recommendations 1.6.1–1.6.4 in section 1.6).
- Social care needs (see recommendations 1.6.5–1.6.6 in section 1.6).

- End of life care needs (see section 1.7).
- Information and support needs for the person and their family members and/or carers (as appropriate) (see section 1.2). **[new 2016]**

1.5.4 The core multidisciplinary team should consist of healthcare professionals and other professionals with expertise in MND, and should include the following:

- Neurologist.
- Specialist nurse.
- Dietitian.
- Physiotherapist.
- Occupational therapist.
- Respiratory physiologist or a healthcare professional who can assess respiratory function.
- Speech and language therapist.
- A healthcare professional with expertise in palliative care (MND palliative care expertise may be provided by the neurologist or nurse in the multidisciplinary team, or by a specialist palliative care professional). **[new 2016]**

1.5.5 The multidisciplinary team should have established relationships with, and prompt access to, the following:

- Clinical psychology and neuropsychology.
- Social care.
- Counselling.
- Respiratory ventilation services.
- Specialist palliative care.
- Gastroenterology.
- Orthotics.

- Wheelchair services.
- Assistive technology services.
- Alternative and augmentative communication (AAC) services.
- Community neurological care teams. **[new 2016]**

1.5.6 Tailor the frequency of the multidisciplinary team assessments to the person's symptoms and needs, with more or less frequent assessments as needed. **[new 2016]**

1.5.7 Ensure arrangements are in place to trigger an earlier multidisciplinary team assessment if there is a significant change in symptoms identified by the person, family members and/or carers (as appropriate), or healthcare professionals. **[new 2016]**

1.5.8 Tailor the multidisciplinary team assessment to the person's needs, for example, adjust the format if the person has cognitive or behaviour changes or difficulties with communication. **[new 2016]**

1.5.9 Inform all healthcare professionals and social care practitioners involved in the person's care about key decisions reached with the person and their family members and/or carers (as appropriate). **[new 2016]**

1.5.10 Ensure that all healthcare professionals and social care practitioners involved in the person's care are aware that MND symptoms may get worse quickly, and that people with MND will need repeated, ongoing assessments. Priority should be given to ensuring continuity of care and avoiding untimely case closure. **[new 2016]**

1.5.11 Consider referral to a specialist palliative care team for people with current or anticipated significant or complex needs, for example, psychological or social distress, troublesome or rapidly progressing symptoms and complex future care planning needs. **[new 2016]**

1.5.12 For guidance on the use of riluzole for people with MND, see the NICE technology appraisal guidance on the use of riluzole (Rilutek) for the treatment of motor neurone disease. **[new 2016]**

1.6 Psychological and social care support

1.6.1 During multidisciplinary team assessments and other appointments, discuss the psychological and emotional impact of MND with the person and ask whether they have any psychological or support care needs. Topics to discuss may include the following:

- Their understanding of MND and how it affects daily living.
- Accepting and coping with the diagnosis and prognosis, including concerns and fears about dying.
- Their ability to continue with current work and usual activities.
- Adjusting to changes in their life and their perception of self.
- Changes in relationships, familial roles and family dynamics.
- Sexuality and intimacy.
- Concerns about their family members and/or carers.
- Decision-making. **[new 2016]**

1.6.2 Offer the person information about sources of emotional and psychological support, including support groups and online forums. If needed, refer the person to counselling or psychology services for a specialist assessment and support. **[new 2016]**

1.6.3 During multidisciplinary team assessments and other appointments, discuss the psychological and emotional impact of MND with family members and/or carers (as appropriate), and ask whether they have any psychological or social care support needs. Topics to discuss may include the following:

- Their understanding of MND and how it affects daily living.
- Accepting and coping with the diagnosis and prognosis, including concerns and fears about the person with MND dying.
- Adjusting to changes in their life.

- Changes in relationships, familial roles and family dynamics, including their change to a carer role (if appropriate).
- Sexuality and intimacy.
- Involvement in decision-making.
- Impact on other family members and/or carers.
- Their ability and willingness to provide personal care and operate equipment. **[new 2016]**

1.6.4 Offer family members and/or carers (as appropriate) information about respite care and sources of emotional and psychological support, including support groups, online forums and counselling or psychology services. **[new 2016]**

1.6.5 A social care practitioner with knowledge of MND or rapidly progressive complex disabilities should discuss the person's needs and preferences for social care, and provide information and support for them to access the following:

- Personal care, ensuring there is continuity of care with familiar workers, so that wherever possible, personal care and support is carried out by workers known to the person and their family members and/or carers (as appropriate).
- Equipment and practical support (see section 1.9).
- Financial support and advice (for example, money management, how to access carers' and disability benefits and grants, continuing healthcare funding and funeral expenses).
- Support to engage in work, social activities and hobbies, such as access to social media and physical access to activities outside their home.
- Respite care. **[new 2016]**

1.6.6 Be aware that as MND progresses, people may develop communication problems and have difficulty accessing support or services. For example, they may be unable to access a call centre. Ensure people are given different ways of getting in touch with support or services, and a designated contact if possible. **[new 2016]**

1.7 *Planning for end of life*

1.7.1 Offer the person with MND the opportunity to discuss their preferences and concerns about care at the end of life at trigger points such as: at diagnosis, if there is a significant change in respiratory function, or if interventions such as gastrostomy or non-invasive ventilation are needed. Be sensitive about the timing of discussions and take into account the person's current communication ability, cognitive status and mental capacity. **[new 2016]**

1.7.2 Be prepared to discuss end of life issues whenever people wish to do so. **[new 2016]**

1.7.3 Provide support and advice on advance care planning for end of life. Topics to discuss may include:

- What could happen at the end of life, for example, how death may occur.
- Providing anticipatory medicines in the home.
- Advance care planning, including Advance Decisions to Refuse Treatment (ADRT) and Do Not Attempt Resuscitation (DNACPR) orders, and Lasting Power of Attorney.
- How to ensure advance care plans will be available when needed, for example, including the information on the person's Summary Care Record.
- When to involve specialist palliative care.
- Areas that people might wish to plan for, such as:
    - what they want to happen (for example, their preferred place of death)
    - what they do not want to happen (for example, being admitted to hospital)
    - who will represent their decisions, if necessary
    - what should happen if they develop an intercurrent illness. **[new 2016]**

1.7.4 Think about discussing advance care planning with people at an earlier opportunity if you expect their communication ability, cognitive status or mental capacity to get worse. **[new 2016]**

1.7.5 Offer people the opportunity to talk about, and review any existing, ADRT, DNACPR orders and Lasting Power of Attorney when interventions such as gastrostomy and non-invasive ventilation are planned. **[new 2016]**

1.7.6 Provide additional support as the end of life approaches, for example, additional social or nursing care to enable informal carers and family to reduce their carer responsibilities and spend time with the person with MND. **[new 2016]**

1.7.7 Towards the end of life, ensure there is prompt access to the following, if not already provided:

- A method of communication that meets the person's needs, such as an AAC system.
- Specialist palliative care.
- Equipment, if needed, such as syringe drivers, suction machines, riser–recliner chair, hospital bed, commode and hoist.
- Anticipatory medicines, including opioids and benzodiazepines to treat breathlessness, and antimuscarinic medicines to treat problematic saliva and respiratory secretions. **[new 2016]**

1.7.8 Offer bereavement support to family members and/or carers (as appropriate). **[new 2016]**

1.8 Managing symptoms

Pharmacological treatments for muscle problems

1.8.1 Discuss the available treatment options for muscle problems. Take into account the person's needs and preferences, and whether they have any difficulties taking medicine (for example, if they have problems swallowing). **[new 2016]**

1.8.2 Consider quinine[1] as first-line treatment for muscle cramps in people with MND. If quinine is not effective, not tolerated or contraindicated, consider baclofen[1] instead as second-line treatment. If baclofen is not effective, not tolerated or contraindicated, consider tizanidine[1], dantrolene[1] or gabapentin[1]. **[new 2016]**

1.8.3 Consider baclofen, tizanidine, dantrolene[1] or gabapentin[1] to treat muscle stiffness, spasticity or increased tone in people with MND. If these treatments are not effective, not tolerated or contraindicated, consider referral to a specialist service for the treatment of severe spasticity. **[new 2016]**

1.8.4 Review the treatments for muscle problems during multidisciplinary team assessments, ask about how the person is finding the treatment, whether it is working and whether they have any adverse side effects. **[new 2016]**

Exercise programmes

1.8.5 Consider an exercise programme for people with MND to:

- maintain joint range of movement
- prevent contractures
- reduce stiffness and discomfort
- optimise function and quality of life. **[new 2016]**

1.8.6 Choose a programme that is appropriate to the person's level of function and tailored to their needs, abilities and preferences. Take into account factors such as postural needs and fatigue. The programme might be a resistance programme, an active-assisted programme or a passive programme. **[new 2016]**

1.8.7 Check that family members and/or carers (as appropriate) are willing and able to help with exercise programmes. **[new 2016]**

1.8.8 Give advice to the person and their family members and/or carers (as appropriate) about safe manual handling. **[new 2016]**

1.8.9 If a person needs orthoses to help with muscle problems, they should be referred to orthotics services without delay, and the orthoses should be provided without delay. **[new 2016]**

Saliva problems

1.8.10 If a person with MND has problems with saliva, assess the volume and viscosity of the saliva and the person's respiratory function, swallowing, diet, posture and oral care. **[new 2016]**

1.8.11 If a person with MND has problems with drooling of saliva (sialorrhoea), provide advice on swallowing, diet, posture, positioning, oral care and suctioning. **[new 2016]**

1.8.12 Consider a trial of antimuscarinic medicine[1] as the first-line treatment for sialorrhoea in people with MND. **[new 2016]**

1.8.13 Consider glycopyrrolate[1] as the first-line treatment for sialorrhoea in people with MND who have cognitive impairment, because it has fewer central nervous system side effects. **[new 2016]**

1.8.14 If first-line treatment for sialorrhoea is not effective, not tolerated or contraindicated, consider referral to a specialist service for Botulinum toxin A[1]. **[new 2016]**

1.8.15 If a person with MND has thick, tenacious saliva:

- review all current medicines, especially any treatments for sialorrhoea
- provide advice on swallowing, diet, posture, positioning, oral care, suctioning and hydration
- consider treatment with humidification, nebulisers and carbocisteine. **[new 2016]**

1.9 Equipment and adaptations to aid activities of daily living and mobility

1.9.1 Healthcare professionals and social care practitioners, which will include physiotherapists and occupational therapists, should assess and anticipate changes in the person's daily living needs, taking into account the following:

- Activities of daily living, including personal care, dressing and bathing, housework, shopping, food preparation, eating and drinking, and ability to continue with current work and usual activities.

- Mobility and avoiding falls and problems from loss of dexterity.
- The home environment and the need for adaptations.
- The need for assistive technology, such as environmental control systems. **[new 2016]**

1.9.2 Provide equipment and adaptations that meet the person's needs without delay, so that people can participate in activities of daily living and maintain their quality of life as much as possible. **[new 2016]**

1.9.3 Refer people to specialist services without delay if assistive technology such as environmental control systems is needed. People should be assessed and assistive technology provided without delay. **[new 2016]**

1.9.4 Refer people to wheelchair services without delay if needed. Wheelchair needs should be assessed and a manual and/or powered wheelchair that meets the person's needs should be provided without delay. **[new 2016]**

1.9.5 Ensure that equipment, adaptations, daily living aids, assistive technology and wheelchairs meet the changing needs of the person and their family and/or carers (as appropriate) to maximise mobility and participation in activities of daily living. **[new 2016]**

1.9.6 Ensure regular, ongoing monitoring of the person's mobility and daily life needs and abilities as MND progresses. Regularly review their ability to use equipment and to adapt equipment as necessary. **[new 2016]**

1.9.7 Healthcare professionals, social care practitioners and other services providing equipment should liaise to ensure that all equipment provided can be integrated, for example, integrating AAC aids and devices and environmental control systems with wheelchairs. **[new 2016]**

1.9.8 Enable prompt access and assessment for funding for home adaptation. If the person is not eligible for funding, continue to offer information and support in arranging home environment adaptations. **[new 2016]**

1.10 Nutrition and gastrostomy

Please also refer to the recommendations in NICE's guideline on nutrition support for adults.

1.10.1 At diagnosis and at multidisciplinary team assessments, or if there are any concerns about weight, nutrition or swallowing, assess the person's weight, diet, nutritional intake, fluid intake, hydration, oral health, feeding, drinking and swallowing, and offer support, advice and interventions as needed. **[new 2016]**

1.10.2 Assess the person's diet, hydration, nutritional intake and fluid intake by taking into account:

- fluids and food intake versus nutritional and hydration needs
- nutritional supplements, if needed
- appetite and thirst
- gastrointestinal symptoms, such as nausea or constipation
- causes of reduced oral intake (for example, swallowing difficulties, limb weakness or the possibility of low mood or depression causing loss of appetite). **[new 2016]**

1.10.3 Assess the person's ability to eat and drink by taking into account:

- the need for eating and drinking aids and altered utensils to help them take food from the plate to their mouth
- the need for help with food and drink preparation
- advice and aids for positioning, seating and posture while eating and drinking
- dealing with social situations (for example, eating out). **[new 2016]**

1.10.4 Arrange for a clinical swallowing assessment if swallowing problems are suspected. **[new 2016]**

1.10.5 Assess and manage factors that may contribute to problems with swallowing, such as:

- positioning
- seating
- the need to modify food and drink consistency and palatability

- respiratory symptoms and risk of aspiration and/or choking
- fear of choking and psychological considerations (for example, wanting to eat and drink without assistance in social situations). **[new 2016]**

1.10.6 Discuss gastrostomy at an early stage, and at regular intervals as MND progresses, taking into account the person's preferences and issues, such as ability to swallow, weight loss, respiratory function, effort of feeding and drinking and risk of choking. Be aware that some people will not want to have a gastrostomy. **[new 2016]**

1.10.7 Explain the benefits of early placement of a gastrostomy, and the possible risks of a late gastrostomy (for example, low critical body mass, respiratory complications, risk of dehydration, different methods of insertion, and a higher risk of mortality and procedural complications). **[new 2016]**

1.10.8 If a person is referred for a gastrostomy, it should take place without unnecessary delay. **[new 2016]**

1.10.9 Pay particular attention to the nutritional and hydration needs of people with MND who have frontotemporal dementia and who lack mental capacity. The multidisciplinary team assessment should include the support they need from carers, and their ability to understand the risks of swallowing difficulties. **[new 2016]**

1.10.10 Before a decision is made on the use of gastrostomy for a person with MND who has frontotemporal dementia, the neurologist from the multidisciplinary team should assess the following:

- The person's ability to make decisions and to give consent[2].
- The severity of frontotemporal dementia and cognitive problems.
- Whether the person is likely to accept and cope with treatment.

  Discuss with the person's family members and/or carers (as appropriate; with the person's consent if they have the ability to give it). **[new 2016]**

1.11 Communication

1.11.1 When assessing speech and communication needs during multidisciplinary team assessments and other appointments, discuss face-to-face and remote communication, for example, using the telephone, email, the Internet and social media. Ensure that the assessment and review is carried out by a speech and language therapist without delay. **[new 2016]**

1.11.2 Provide AAC equipment that meets the needs of the person without delay to maximise participation in activities of daily living and maintain quality of life. The use of both low-level technologies, for example, alphabet, word or picture boards and high-level technologies, for example, PC or tablet-based voice output communication aids may be helpful. Review the person's communication needs during multidisciplinary team assessments. **[new 2016]**

1.11.3 Liaise with, or refer the person with MND to, a specialised NHS AAC hub if complex high technology AAC equipment (for example, eye gaze access) is needed or is likely to be needed. **[new 2016]**

1.11.4 Involve other healthcare professionals, such as occupational therapists, to ensure that AAC equipment is integrated with other assistive technologies, such as environmental control systems and personal computers or tablets. **[new 2016]**

1.11.5 Ensure regular, ongoing monitoring of the person's communication needs and abilities as MND progresses, and review their ability to use AAC equipment. Reassess and liaise with a specialised NHS AAC hub if needed. **[new 2016]**

1.11.6 Provide ongoing support and training for the person with MND, and their family members and/or carers (as appropriate), in using AAC equipment and other communication strategies. **[new 2016]**

1.12 Respiratory function and respiratory symptoms

1.12.1 Assess and monitor the person's respiratory function and symptoms. Treat people with MND and worsening respiratory impairment for reversible causes (for example, respiratory tract infections or secretion problems) before considering other treatments. **[new 2016]**

1.12.2 Offer non-invasive ventilation as treatment for people with respiratory impairment (see section 1.14). Decisions to offer non-invasive ventilation should be made by the multidisciplinary team in conjunction with the respiratory ventilation service, and the person (see recommendations 1.5.1–1.5.5). **[new 2016]**

1.12.3 Consider urgent introduction of non-invasive ventilation for people with MND who develop worsening respiratory impairment and are not already using non-invasive ventilation. **[new 2016]**

1.12.4 Consider opioids[1] as an option to relieve symptoms of breathlessness. Take into account the route of administration and acquisition cost of medicines. **[new 2016]**

1.12.5 Consider benzodiazepines[1] to manage breathlessness that is exacerbated by anxiety. Take into account the route of administration and acquisition cost of medicines. **[new 2016]**

1.13 Cough effectiveness

1.13.1 Offer cough augmentation techniques such as manual assisted cough to people with MND who cannot cough effectively. **[new 2016]**

1.13.2 Consider unassisted breath stacking and/or manual assisted cough as the first-line treatment for people with MND who have an ineffective cough. **[new 2016]**

1.13.3 For people with bulbar dysfunction, or whose cough is ineffective with unassisted breath stacking, consider assisted breath stacking (for example, using a lung volume recruitment bag). **[new 2016]**

1.13.4 Consider a mechanical cough assist device if assisted breath stacking is not effective, and/or during a respiratory tract infection. **[new 2016]**

1.14 *Non-invasive ventilation*

Information and support about non-invasive ventilation

1.14.1 Offer to discuss the possible use of non-invasive ventilation with the person and (if the person agrees) their family and carers, at an appropriate time and in a sensitive manner. This may be at one or more of the following times:

- soon after MND is first diagnosed
- when monitoring respiratory function
- when respiratory function deteriorates
- if the person asks for information. **[2010]**

1.14.2 Discussions about non-invasive ventilation should be appropriate to the stage of the person's illness, carried out in a sensitive manner and include information on:

- the possible symptoms and signs of respiratory impairment (see box 1)
- the purpose, nature and timing of respiratory function tests, and explanations of the test results
- how non-invasive ventilation (as a treatment option) can improve symptoms associated with respiratory impairment and can be life prolonging, but does not stop progression of the underlying disease. **[2010, amended 2016]**

1.14.3 When discussing non-invasive ventilation, explain the different ways that people can manage their breathlessness symptoms. This should include:

- non-invasive ventilation, and its advantages and disadvantages
- using non-invasive ventilation at different points in the course of the person's lifetime
- the possibility of the person becoming dependent on non-invasive ventilation
- options for treating any infections
- support and information on how to recognise and cope with a distressing situation

- the role of medication for breathing problems
- psychological techniques and support. **[new 2016]**

1.14.4 Check that the person thinking about non-invasive ventilation:

- understands what non-invasive ventilation is and what it can achieve
- recognises the need for regular review
- has enough information about non-invasive ventilation and other options for breathing problems to make decisions about how and when to use it.
- understands possible problems with compatibility with other equipment, for example, eye gaze access systems. **[new 2016]**

1.14.5 Explain that non-invasive ventilation can be stopped at any time. Reassure people that they can ask for help and advice if they need it, especially if they are dependent on non-invasive ventilation for 24 hours a day, or become distressed when attempting to stop it. Inform people that medicines can be used to alleviate symptoms (see recommendation 1.14.29). **[new 2016]**

1.14.6 Ensure that families and carers:

- have an initial assessment if the person they care for decides to use non-invasive ventilation, which should include:
  - their ability and willingness to assist in providing non-invasive ventilation
  - their training needs
- have the opportunity to discuss any concerns they may have with members of the multidisciplinary team, the respiratory ventilation service and/or other healthcare professionals. **[2010]**

Identification and assessment of respiratory impairment

Symptoms and signs

1.14.7 Monitor the symptoms and signs listed in box 1 to detect potential respiratory impairment. **[2010, amended 2016]**

Box 1 Symptoms and signs of potential respiratory impairment

Symptoms	Signs
Breathlessness	Increased respiratory rate
Orthopnoea	Shallow breathing
Recurrent chest infections	Weak cough[1]
Disturbed sleep	Weak sniff
Non-refreshing sleep	Abdominal paradox (inward movement of the abdomen during inspiration)
Nightmares	Use of accessory muscles of respiration
Daytime sleepiness	Reduced chest expansion on maximal inspiration
Poor concentration and/or memory	
Confusion	
Hallucinations	
Morning headaches	
Fatigue	
Poor appetite	
[1] Weak cough could be assessed by measuring peak cough flow.	

Respiratory function tests

1.14.8 As part of the initial assessment to diagnose MND, or soon after diagnosis, a healthcare professional from the multidisciplinary team who has appropriate competencies should perform the following tests (or arrange for them to be performed) to establish the person's baseline respiratory function:

- oxygen saturation measured by pulse oximetry (SpO_2):
    - this should be a single measurement of SpO_2 with the person at rest and breathing room air

  - if it is not possible to perform pulse oximetry locally, refer the person to a respiratory ventilation service.

    Then one or both of the following:

- forced vital capacity (FVC) or vital capacity (VC)[3]
- sniff nasal inspiratory pressure (SNIP) and/or maximal inspiratory pressure (MIP). **[2010]**

1.14.9 If the person has severe bulbar impairment or severe cognitive problems that may be related to respiratory impairment:

- ensure that SpO_2 is measured (at rest and breathing room air)
- do not perform the other respiratory function tests (FVC, VC, SNIP and MIP) if interfaces are not suitable for the person. **[2010]**

1.14.10 A healthcare professional with appropriate competencies should perform the respiratory function tests every 2–3 months, although tests may be performed more or less often depending on:

- whether there are any symptoms and signs of respiratory impairment (see box 1)
- the rate of progression of MND
- the person's preference and circumstances. **[2010, amended 2016]**

1.14.11 Perform arterial or capillary blood gas analysis if the person's SpO_2 (measured at rest and breathing room air):

- is less than or equal to 92% if they have known lung disease
- is less than or equal to 94% if they do not have lung disease.

  If it is not possible to perform arterial or capillary blood gas analysis locally, refer the person to a respiratory ventilation service. **[2010]**

1.14.12 If the person's SpO_2 (measured at rest and breathing room air) is greater than 94%, or 92% for those with lung disease, but they have sleep-related respiratory symptoms:

- consider referring them to a respiratory ventilation service for continuous nocturnal (overnight) oximetry and/or a limited sleep study **and**
- discuss both the impact of respiratory impairment and treatment options with the patient and (if the person agrees) their family and carers. **[2010]**

1.14.13 If the person's arterial partial pressure of carbon dioxide ($PaCO_2$) is greater than 6 kPa:

- refer them urgently to a respiratory ventilation service (to be seen within 1 week) **and**
- explain the reasons for and implications of the urgent referral to the person and (if the person agrees) their family and carers. **[2010]**

1.14.14 If the person's $PaCO_2$ is less than or equal to 6 kPa but they have any symptoms or signs of respiratory impairment, particularly orthopnoea (see recommendation 1.14.15):

- refer them to a respiratory ventilation service for nocturnal (overnight) oximetry and/or a limited sleep study **and**
- discuss both the impact of respiratory impairment and treatment options with the person and (if the person agrees) their family and/or carers (as appropriate). **[2010]**

1.14.15 If any of the results listed in box 2 is obtained, discuss with the person and (if appropriate) their family and carers:

- their respiratory impairment
- their treatment options
- possible referral to a respiratory ventilation service for further assessment based on discussion with the person, and their wishes. **[2010, amended 2016]**

Box 2 Results of respiratory function tests

Forced vital capacity (FVC) or vital capacity (VC)	Sniff nasal inspiratory pressure (SNIP) and/or maximal inspiratory pressure (MIP) (if both tests are performed, base the assessment on the better respiratory function reading)

FVC or VC less than 50% of predicted value FVC or VC less than 80% of predicted value plus any symptoms or signs of respiratory impairment (see recommendation 1.14.7), particularly orthopnoea	SNIP or MIP less than 40 cmH_2O SNIP or MIP less than 65 cmH_2O for men or 55 cmH_2O for women plus any symptoms or signs of respiratory impairment (see recommendation 1.14.7), particularly orthopnoea Repeated regular tests show a rate of decrease of SNIP or MIP of more than 10 cm H_2O per 3 months

People with a diagnosis of frontotemporal dementia

1.14.16 Base decisions on respiratory function tests for a person with a diagnosis of frontotemporal dementia on considerations specific to their needs and circumstances, such as:

- their ability to give consent[2]
- their understanding of the tests
- their tolerance of the tests and willingness to undertake them
- the impact on their family and carers
- whether they are capable of receiving non-invasive ventilation. **[2010, amended 2016]**

Non-invasive ventilation for treatment of respiratory impairment in people with MND

1.14.17 Offer a trial of non-invasive ventilation if the person's symptoms and signs and the results of the respiratory function tests indicate that the person is likely to benefit from the treatment. **[2010, amended 2016]**

1.14.18 Consider a trial of non-invasive ventilation for a person who has severe bulbar impairment or severe cognitive problems that may be related to respiratory impairment only if they may benefit from an improvement in sleep-related symptoms or correction of hypoventilation. **[2010, amended 2016]**

1.14.19 Before starting non-invasive ventilation, the multidisciplinary team together with the respiratory ventilation service should carry out and coordinate a patient-centred risk assessment, after discussion with the person and their family and carers. This should consider:

- the most appropriate type of non-invasive ventilator and interfaces, based on the person's needs and lifestyle factors and safety
- the person's tolerance of the treatment
- the risk, and possible consequences, of ventilator failure
- the power supply required, including battery back-up
- how easily the person can get to hospital
- risks associated with travelling away from home (especially abroad)
- whether a humidifier is required
- issues relating to secretion management
- the availability of carers. [2010]

1.14.20 Before starting non-invasive ventilation, the multidisciplinary team together with the respiratory ventilation service should prepare a comprehensive care plan, after discussion with the person and their family and carers (who should be offered a copy of the plan). This should cover:

- long-term support provided by the multidisciplinary team
- the initial frequency of respiratory function tests and monitoring of respiratory impairment
- the frequency of clinical reviews of symptomatic and physiological changes
- the provision of carers
- arrangements for device maintenance and 24-hour emergency clinical and technical support
- secretion management and respiratory physiotherapy assessment, including cough augmentation (if required)

- training in and support for the use of non-invasive ventilation for the person and their family and carers
- regular opportunities to discuss the person's wishes in relation to continuing or withdrawing non-invasive ventilation. [2010, amended 2016]

1.14.21 When starting non-invasive ventilation:

- perform initial acclimatisation during the day when the person is awake
- usually start regular treatment at night, before and during sleep
- gradually build up the person's hours of use as necessary. [2010]

1.14.22 Continue non-invasive ventilation if the clinical reviews show:

- symptomatic and/or physiological improvements for a person without severe bulbar impairment and without severe cognitive problems
- an improvement in sleep-related symptoms for a person with severe bulbar impairment or with severe cognitive problems that may be related to respiratory impairment. [2010]

1.14.23 Provide the person and their family and/or carers (as appropriate) with support and assistance to manage non-invasive ventilation. This should include:

- training on using non-invasive ventilation and ventilator interfaces, for example:
    - emergency procedures
    - night-time assistance if the person is unable to use the equipment independently (for example, emergency removal or replacement of interfaces)
    - how to use the equipment with a wheelchair or other mobility aids if required
    - what to do if the equipment fails
- assistance with secretion management
- information on general palliative strategies
- an offer of ongoing emotional and psychological support for the person and their family and carers. [2010, amended 2016]

1.14.24 Discuss all decisions to continue or withdraw non-invasive ventilation with the person and (if the person agrees) their family and carers. **[2010]**

1.14.25 Before a decision is made on the use of non-invasive ventilation for a person with a diagnosis of frontotemporal dementia, the multidisciplinary team together with the respiratory ventilation service should carry out an assessment that includes:

- the person's capacity to make decisions and to give consent[2]
- the severity of dementia and cognitive problems
- whether the person is likely to accept treatment
- whether the person is likely to achieve improvements in sleep-related symptoms and/or behavioural improvements
- a discussion with the person's family and/or carers (with the person's consent if they have the capacity to give it). **[2010, amended 2016]**

1.14.26 Consider prescribing medicines to help ease breathlessness that people using non-invasive ventilation can take on an 'as-needed' basis at home, for example, opioids[1] or benzodiazepines[1]. **[new 2016]**

1.14.27 Inform services that may see the person in crisis situations, such as their GP and services that provide emergency or urgent care, that the person is using non-invasive ventilation. **[new 2016]**

Stopping non-invasive ventilation

1.14.28 The healthcare professionals responsible for starting non-invasive ventilation treatment in people with MND should ensure that support is available for other healthcare professionals who may be involved if there is a plan to stop non-invasive ventilation, including the legal and ethical implications. **[new 2016]**

1.14.29 If a person on continuous non-invasive ventilation wishes to stop treatment, ensure that they have support from healthcare professionals with knowledge and expertise of:

- stopping non-invasive ventilation

- the ventilator machine
- palliative medicines (see the NICE guideline on care of dying adults in the last days of life)
- supporting the person, family members and/or carers (as appropriate)
- supporting other healthcare professionals involved with the person's care
- legal and ethical frameworks and responsibilities. **[new 2016]**

1.14.30 If a person on continuous non-invasive ventilation wishes to stop treatment, seek advice from healthcare professionals who have knowledge and experience of stopping non-invasive ventilation. **[new 2016]**

1.14.31 Healthcare professionals involved in stopping non-invasive ventilation should have up-to-date knowledge of the law regarding the Mental Capacity Act, DNACPR, ADRT orders, and Lasting Power of Attorney. **[new 2016]**

To find out what NICE has said on topics related to this guideline, see our web pages on motor neurone disease, dementia, nutrition and end of life care.

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[1] At the time of publication (February 2016), these medicines did not have a UK marketing authorisation for this indication. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines for further information.

[2] See Mental Capacity Act 2005.

[3] The difference between the measurement of vital capacity and forced vital capacity is very subtle and so either can be used.

Context

Motor neurone disease (MND) is a neurodegenerative condition that affects the brain and spinal cord. MND is characterised by the degeneration of primarily motor neurones, leading to muscle weakness.

The presentation of the disease varies and can be as muscle weakness, wasting, cramps and stiffness of arms and/or legs; problems with speech and/or swallowing or, more rarely, with breathing problems. As the disease progresses, the pattern of symptoms and signs becomes similar, with increasing muscle weakness in the person's arms and legs, problems swallowing and communicating and weakness of the muscles used for breathing, which ultimately leads to death. Most people die within 2–3 years of developing symptoms, but 25% are alive at 5 years and 5–10% at 10 years. The most common type of MND is amyotrophic lateral sclerosis (ALS). There are rarer forms of MND such as progressive muscular atrophy or primary lateral sclerosis, which may have a slower rate of progression.

Every person with MND has an individual progression of the disease. About 10–15% of people with MND will show signs of frontotemporal dementia, which causes cognitive dysfunction and issues in decision-making. A further 35% of people with MND show signs of mild cognitive change, which may affect their ability to make decisions and plan ahead.

MND is a disorder which can affect adults of any age. It is most common in people aged 55–79 years, and onset below the age of 40 years is uncommon. There are approximately 4,000 people living with MND in England and Wales at any one time. The cause of MND is unknown. About 5–10% of people with MND have a family history of the disease and several abnormal genes have been identified.

As there is no cure for MND, care focuses on maintaining functional ability and enabling people with MND and their family members to live as full a life as possible. Early diagnosis, without delay after investigation, may be helpful, as it allows medication and the provision of aids, as well as communication about the disease and advance care planning to be undertaken appropriately.

Care of people with MND varies across England and Wales, with MND care centres and networks providing coordinated multidisciplinary care. However, some people with MND are left isolated and their care is less than ideal. This guideline aims to consider the clinical and cost-effectiveness evidence for the care of people with MND from the time of diagnosis, including communication of the diagnosis, monitoring of disease progression, management of symptoms (in particular muscle weakness, excess secretions, breathing and nutrition problems), ongoing support and services available, mobility, emotional and psychological changes, and the preparation for end of life care. Particular emphasis is placed on the importance of a multidisciplinary team approach to the care and management of people with MND.

Recommendations for research

The Guideline Committee has made the following recommendations for research. The Committee's full set of research recommendations is detailed in the full guideline.

1 Organisation of care

Is a network-based model as effective as a clinic-based model to deliver multidisciplinary care to people with motor neurone disease (MND)?

Why this is important

Multidisciplinary care improves survival in patients with MND. The evidence is drawn from models of multidisciplinary care that use a clinic based approach. However there are other models of care delivery in practice including care networks. Often these alternative models of care have arisen out of necessity in large geographical regions with low density populations. These alternative models may have similar survival advantages to patients with MND and this needs to be established.

2 Cognitive assessment

What is the impact of assessing for cognitive and behaviour change in people with MND on clinical practice, the person and their family and carers? Does repeated assessment provide more benefit than assessment at a single point at diagnosis?

Why this is important

Clinic-based and population-based studies demonstrate that up to 15% of people with MND have frontotemporal dementia. A further third of people with MND have changes in behaviour and cognition. These impairments are present at diagnosis. Their course during the disease has shown varying patterns between studies although several studies have shown that cognitive and behavioural impairments predict poorer survival and increased carer burden. A randomised controlled trial is needed to assess whether formal assessment at diagnosis and/or repeated assessment improves clinical practice, subsequent care of the person and quality of life for the person, their family and carers.

3 Prognostic tools

Is the ALS Prognostic Index an accurate predictor of survival in people with MND under NHS care in England and/or Wales?

Why this is important

Accurate predictions of survival in people with MND would be of great use to clinicians and to the person with MND, their family and carers. Accurate predictions would enable people with MND to be clearer about their prognosis, make plans for the rest of their life and have a well-prepared and dignified transition into the end of life phase. Family members would similarly benefit in being more aware of the likely progression and prepare themselves for the death of their loved one.

Accurate predictions of survival would enable professionals to create and deliver more effective management and care plans and access services when it is most appropriate, for example specialist palliative care.

The ALS Prognostic Index (ALS-PI) was developed in a cohort of people with ALS in the Republic of Ireland and externally validated in a cohort in Italy. However, it has not been validated in people with ALS, primary lateral sclerosis or progressive muscular atrophy in the NHS in England or Wales. The tool needs to be validated in a UK population using a simplified measure of executive function.

4 Saliva

How is excessive drooling of saliva (sialorrhoea) managed in people with MND?

Why this is important

Sialorrhoea affects up to 50% of people with MND and in 42% of these individuals the symptom is poorly controlled. There is no evidence base for clinicians to make decisions with regards to the treatment options available. Antimuscarinics are used first-line but there is no evidence to inform which antimuscarinic and at what dose. Botulinum toxin is used second- or third-line although there is little evidence to guide dosing, which salivary glands to inject and which type of botulinum toxin to use. Currently there is no baseline information about how specialists are using these treatments and this information is required to inform comparative studies.

5 Nutrition

Does a high calorific diet prolong survival of people with MND if initiated following diagnosis or following initiation of feeding using a gastrostomy?

Why this is important

There is little specific guidance on the optimal calorie intake for people with MND. There is growing evidence that people with MND have a hypercatabolic state and have high energy requirements. A large cohort study in the UK has demonstrated that nearly half of people continue to lose weight following gastrostomy and most show no improvement in their weight. A small study has demonstrated that high fat and high carbohydrate feeding may prolong survival in gastrostomy-fed people. A larger randomised trial is needed to inform clinical practice.

6 Augmentative and alternative communication

What is the current pattern of provision and use of augmentative and alternative communication (AAC) by people with MND in England?

Why this is important

Appropriate AAC equipment can have a significant effect on quality of life for people with MND. While the NHS has a responsibility to provide equipment and ongoing support in its use, there are no reliable data on the types of equipment found most useful at different stages of the disease process, or the number of people with MND who may benefit from AAC. A prospective census study of people with MND presenting with early onset of speech problems is needed to establish the current baseline provision and needs of this population and how best to utilise AAC equipment. The programme will begin with the collection and analysis of basic data. It will then progress to patient-related outcomes.

Update information

This guideline amalgamates new guidance on the assessment and management of motor neurone disease (MND) with NICE guideline CG105 (published July 2010), and replaces it.

New recommendations have been added in a number of areas, including recognition and referral, information and support at diagnosis, cognitive assessments, prognostic factors, psychosocial and social support, organisation of care, planning for end of life care, and managing symptoms.

Recommendations are marked as **[new 2016]** if the evidence has been reviewed and the recommendation has been added or updated.

Where recommendations end **[2010]**, the evidence has not been reviewed since the original guideline.

Where recommendations end **[2010, amended 2015]**, the evidence has not been reviewed but changes have been made to the recommendation wording that change the meaning (for example, because of equalities duties or a change in the availability of medicines, or incorporated guidance has been updated). Explanations of the reasons for the changes are given in 'Amended recommendation wording (change to meaning)' for information.

Amended recommendation wording (change to meaning)

Recommendations are labelled **[2010, amended 2016]** if the evidence has not been reviewed but changes have been made to the recommendation wording that change the meaning.

Recommendation in 2010 guideline	Recommendation in current guideline	Reason for change

Discussions should be appropriate to the stage of the patient's illness, carried out in a sensitive manner and include information on: • the possible symptoms and signs of respiratory impairment (see table 1 in recommendation 1.1.7) • the natural progression of MND and what to expect in the future • the purpose, nature and timing of respiratory function tests, and explanations of the test results • available interventions for managing respiratory impairment, including the benefits and limitations of each intervention • accessing and using respiratory equipment, including that for non-invasive ventilation • how non-invasive ventilation (as a treatment option) can improve symptoms associated with respiratory impairment and can be life prolonging, but does not stop progression of the underlying disease	1.14.2 Discussions about non-invasive ventilation should be appropriate to the stage of the person's illness, carried out in a sensitive manner and include information on: • the possible symptoms and signs of respiratory impairment (see box 1) • the purpose, nature and timing of respiratory function tests, and explanations of the test results • how non-invasive ventilation (as a treatment option) can improve symptoms associated with respiratory impairment and can be life prolonging, but does not stop progression of the underlying disease. [2010, amended 2016]	Amended to include specific reference to non-invasive ventilation, and to ensure consistency with new recommendations on information about non-invasive ventilation.

• how non-invasive ventilation can be withdrawn • palliative strategies as an alternative to non-invasive ventilation.(1.1.3)		

1.1.5 Provide the patient and their family and carers with support and assistance to manage non-invasive ventilation. This should include: - training on using non-invasive ventilation and ventilator interfaces, for example: – emergency procedures – night-time assistance if the patient is unable to use the equipment independently (for example, emergency removal or replacement of interfaces) – how to use the equipment with a wheelchair or other mobility aids if required – what to do if the equipment fails - assistance with secretion management - information on general palliative strategies - an offer of ongoing emotional and psychological support[1] for the patient and their family and carers.	1.14.23 Provide the person and their family and/or carers (as appropriate) with support and assistance to manage non-invasive ventilation. This should include: - training on using non-invasive ventilation and ventilator interfaces, for example: – emergency procedures – night-time assistance if the person is unable to use the equipment independently (for example, emergency removal or replacement of interfaces) – how to use the equipment with a wheelchair or other mobility aids if required – what to do if the equipment fails - assistance with secretion management - information on general palliative strategies - an offer of ongoing emotional and psychological support for the person and their family and carers. [2010, amended 2016]	Footnote removed as psychological and social support are included in the new guideline.

1.1.7 Monitor the symptoms and signs listed in table 1 routinely to detect potential respiratory impairment.	1.14.7 Monitor the symptoms and signs listed in box 1 to detect potential respiratory impairment. [2010, amended 2016]	'Routinely' removed as new recommendations for the multidisciplinary team advise on frequency of assessment.
1.1.10 A healthcare professional with appropriate competencies should perform the respiratory function tests every 3 months, although tests may be performed more or less often depending on: • whether there are any symptoms and signs of respiratory impairment (see recommendation 1.1.7) • the rate of progression of MND • the patient's preference and circumstances.	1.14.10 A healthcare professional with appropriate competencies should perform the respiratory function tests every 2–3 months, although tests may be performed more or less often depending on: • whether there are any symptoms and signs of respiratory impairment (see box 1) • the rate of progression of MND • the person's preference and circumstances. [2010, amended 2016]	Time period removed as already included in recommendations for the multidisciplinary team.
1.1.15 If any of the results listed in table 2 is obtained, discuss with the patient and (if the patient agrees) their family and carers: • the impact of respiratory impairment • treatment options • possible referral to a specialist respiratory service for further assessment.	1.14.15 If any of the results listed in box 2 is obtained, discuss with the person and (if appropriate) their family and carers: • their respiratory impairment • their treatment options • possible referral to a respiratory ventilation service for further assessment based on discussion with the person, and their wishes. [2010, amended 2016]	Wording changed for consistency and to emphasise patient choice for referral.

1.1.16 Base decisions on respiratory function tests for a patient with a diagnosis of dementia on considerations specific to their needs and circumstances, such as: - their ability to give consent[3] - their understanding of the tests - their tolerance of the tests and willingness to undertake them - the impact on their family and carers - whether they are capable of receiving non-invasive ventilation.	1.14.16 Base decisions on respiratory function tests for a person with a diagnosis of frontotemporal dementia on considerations specific to their needs and circumstances, such as: - their ability to give consent[2] - their understanding of the tests - their tolerance of the tests and willingness to undertake them - the impact on their family and carers - whether they are capable of receiving non-invasive ventilation. [2010, amended 2016] [2] See Mental Capacity Act 2005.	Amended for consistency without change in meaning. 'dementia' changed to 'frontotemporal dementia'. Footnote wording has changed to refer to the Mental Capacity Act 2005

1.1.17 Offer a trial of non-invasive ventilation if the patient's symptoms and signs and the results of the respiratory function tests indicate that the patient is likely to benefit from the treatment. • Discuss both the benefits and limitations of the intervention with the patient and their family and carers. • Only consider a trial of non-invasive ventilation for a patient who has severe bulbar impairment or severe cognitive problems that may be related to respiratory impairment if they may benefit from an improvement in sleep-related symptoms or correction of hypoventilation.	1.14.17 Offer a trial of non-invasive ventilation if the person's symptoms and signs and the results of the respiratory function tests indicate that the person is likely to benefit from the treatment. [2010, amended 2016] 1.14.18 Consider a trial of non-invasive ventilation for a person who has severe bulbar impairment or severe cognitive problems that may be related to respiratory impairment only if they may benefit from an improvement in sleep-related symptoms or correction of hypoventilation. [2010, amended 2016]	Amended for consistency with new recommendations. New recommendations developed for information following evidence review on stopping non-invasive ventilation.

1.1.19 Before starting non-invasive ventilation, the multidisciplinary team should prepare a comprehensive care plan, after discussion with the patient and their family and carers (who should be offered a copy of the plan). This should cover: • long-term support provided by the multidisciplinary team • the initial frequency of respiratory function tests and monitoring of respiratory impairment • the frequency of clinical reviews of symptomatic and physiological changes • the provision of carers • arrangements for device maintenance and 24-hour emergency clinical and technical support • secretion management and respiratory physiotherapy assessment, including cough-assist therapy (if required) • training in and support for the use of non-invasive ventilation for the patient and their family and carers	1.14.20 Before starting non-invasive ventilation, the multidisciplinary team in conjunction with the ventilation service should prepare a comprehensive care plan, after discussion with the person and their family and carers (who should be offered a copy of the plan). This should cover: • long-term support provided by the multidisciplinary team • the initial frequency of respiratory function tests and monitoring of respiratory impairment • the frequency of clinical reviews of symptomatic and physiological changes • the provision of carers • arrangements for device maintenance and 24-hour emergency clinical and technical support • secretion management and respiratory physiotherapy assessment, including cough-assist therapy (if required) • training in and support for the use of non-invasive ventilation for the person and their family and carers • regular opportunities to discuss the person's wishes in relation to	Part of last bullet point deleted as replaced by recommendations on Planning for end of life.

- regular opportunities to discuss the patient's wishes in relation to continuing or withdrawing non-invasive ventilation, and other end-of-life considerations (see also recommendations 1.1.24 and 1.1.25).	continuing or withdrawing non-invasive ventilation. [2010, amended 2016]	
1.1.23 Before a decision is made on the use of non-invasive ventilation for a patient with a diagnosis of dementia, the neurologist from the multidisciplinary team should carry out an assessment that includes: - the patient's capacity to make decisions and to give consent[3] - the severity of dementia and cognitive problems - whether the patient is likely to accept treatment - whether the patient is likely to achieve improvements in sleep-related symptoms and/or behavioural improvements - a discussion with the patient's family and/or carers (with the patient's consent if they have the capacity to give it).	1.14.25 Before a decision is made on the use of non-invasive ventilation for a person with a diagnosis of frontotemporal dementia, the multidisciplinary team in conjunction with the ventilation service should carry out an assessment that includes: - the person's capacity to make decisions and to give consent[2] - the severity of dementia and cognitive problems - whether the person is likely to accept treatment - whether the person is likely to achieve improvements in sleep-related symptoms and/or behavioural improvements - a discussion with the person's family and/or carers (with the person's consent if they have the capacity to give it). [2010, amended 2016] [2] See Mental Capacity Act 2005.	Amended to update wording and reflect changes to law. 'dementia' changed to 'frontotemporal dementia' and footnote changed to reflect Mental Capacity Act. Footnote wording has changed to refer to the Mental Capacity Act 2005.

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ADULT SERVICES COMMITTEE

12 July 2018

Report of: Director of Adult and Community Based Services

Subject: ACCESS TO TRANSPORT FOR PEOPLE WITH A DISABILITY

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1. TYPE OF DECISION/APPLICABLE CATEGORY

1.1 For information.

2. PURPOSE OF REPORT

2.1 To provide an update to the Adult Services Committee on the review of access to transport for people with a disability.

3. BACKGROUND

3.1 Hartlepool Borough Council is committed to supporting local citizens through effective consultation. Transport and access to transport within the Borough is regarded as one of the top three priorities when consulting with adults with a disability.

3.2 The Equality Act 2010 came into force in October 2010 and most transport is covered by the rules on services to the public in Equality Act Part 3.

3.3 The Disability Rights Commission (DRC) issued a statutory Code of Practice on provision and use of transport vehicles in 2006 which sets out in some detail how the DRC saw the transport rules working under the former Disability Discrimination Act 1995 (DDA).

3.4 Although the DDA has now been superseded by the Equality Act 2010, it has been referred to in past cases and is still helpful.

3.5 The Council's Audit and Governance Committee conducted a review of access to transport for people with a disability, following a referral from Adult Services Committee and the outcome was reported back to Adult Services Committee in July 2017.

3.6 The Adult Services Committee response to the findings included a request for the Council's passenger transport section to provide a further update to members. Jane Brown, Passenger Transport Team Manager is in attendance to provide an update via a short presentation.

4. UPDATE ON ACTION PLAN

4.1 An update on the action plan presented to Committee on 27 July 2017 is attached as **Appendix 1**.

5. RISK IMPLICATIONS

5.1 There are no risk implications identified associated with this report.

6. FINANCIAL CONSIDERATIONS

6.1 There are no financial implications identified associated with this report.

7. LEGAL CONSIDERATIONS

7.1 There are no legal consideration identified associated with this report.

8. CHILD AND FAMILY POVERTY CONSIDERATIONS

8.1 There are no child and family poverty considerations identified.

9. EQUALITY AND DIVERSITY CONSIDERATIONS

9.1 Hartlepool Borough Council is required to work within the principles of the Equality Act and where it procures, provides or promotes transportation within the Borough it must consider the impact of its services for people with a disability ensuring equality of access to transport as prescribed within the Disability Rights Commission Code of Practice.

10. STAFF CONSIDERATIONS

10.1 There are no staffing considerations associated with this report.

11. ASSET MANAGEMENT CONSIDERATIONS

11.1 There are no asset management considerations associated with this report.

12. RECOMMENDATION

12.1 It is recommended that the Adult Services Committee note the report, the update provided via a presentation and the updated action plan.

13. REASONS FOR RECOMMENDATIONS

13.1 The review by the Audit and Governance Committee highlighted concerns regarding access to transport for adults with a disability. The Adult Services Committee requested updates on progress to address these concerns.

14. BACKGROUND PAPERS

Adult Services Committee, Agenda and Minutes 27 July 2017
www.hartlepool.gov.uk/meetings/meeting/3605/adult_services_committee

15. CONTACT OFFICERS

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7.1 Appendix 1

AUDIT AND GOVERNANCE SCRUTINY ENQUIRY ACTION PLAN

NAME OF COMMITTEE: Adult Services Committee - Update March 2018

NAME OF SCRUTINY ENQUIRY: Access to Transport for People with a Disability

RECOMMENDATION	EXECUTIVE RESPONSE / PROPOSED ACTION+	FINANCIAL / OTHER IMPLICATIONS	UPDATE
(a) That a mapping exercise be undertaken to explore the viability of a travel membership club for people with disabilities to access, as and when required, with a detailed exploration of the following areas:-	(a) A number of discussions have been held with local providers who expressed an interest. • A consortium of local businesses were considering the option of developing and investing in a scheme to support local citizens, however following due diligence concluded that there was little evidence to suggest it would be successful or cost neutral. • A private provider with experience of providing transport for adults with disabilities has expressed interest in purchasing a vehicle to set up an alternative travel service. • Community Travel Clubs - Clubs can be established in geographical areas by a number of community groups, Transport Champions, Parish Councils etc to consider the travel needs of individuals within their community. The travel club determines the needs of its members and	Previous 'Dial a Ride' running costs in excess of £250,000 per annum to operate. Cost to run service is unknown, a provider is willing to contribute towards set up costs. Costs of journeys will vary depending on the needs of each group; the charge is made up of proportional costs of the vehicle, driver and fuel. Several community travel clubs are operating via Passenger transport none of	A private provider continues to provide a community travel club, having purchased a wheelchair accessible vehicle. The service is open to all ages and provides door to door transport for people with a disability or health problem. The service can be used for short journeys such as shopping, visiting friends, attending health appointments and social occasions.

RECOMMENDATION	EXECUTIVE RESPONSE / PROPOSED ACTION[+]	FINANCIAL / OTHER IMPLICATIONS	UPDATE
	the Local Authority can provide the service required The Council's Passenger Transport Service has a variety of vehicles available to support a Community Travel Club scheme, ranging from 67 seat coaches, 33 seat buses and 17 seat minibuses, including vehicles suitable for those using mobility aids. These vehicles would potentially be available to travel clubs outside of school travel times, evenings and weekends. Transport provision would be flexible and delivered on a demand lead basis across a varied geographical area. The cost of each journey will be predetermined and shared between the patrons using the service. There is interest from a provider operating a patient transport service in Durham (NHS - transport) which has a number of vehicles and volunteer drivers. The provider is interested in exploring options to extend into Hartlepool.	which are subsidised routes. No cost to the Council Service is funded through a contract with Durham CCG an Durham CC (public health grant)	Presentation to Committee from Jayne Brown, Passenger Transport Team Manager
(i) Identification of the actual number of people affected;	(i) Information provided from a number of sources, no definitive list of the number of people reliant on a wheelchair. • Office for National Statistics (2011 census) - 1.9% of the UK population uses a wheelchair (Hartlepool = 1,757). • Number of people claiming Severe Disablement Allowance (SDA) in Hartlepool = 480. • North Tees and Hartlepool NHS Trust has 3,709 adults and 452 children registered with	A definitive number of people cannot be predicted.	(i) Estimates suggest that over 1000 people in Hartlepool may not have access to a vehicle

RECOMMENDATION	EXECUTIVE RESPONSE / PROPOSED ACTION+	FINANCIAL / OTHER IMPLICATIONS	UPDATE
	wheelchair services (Hartlepool = 1,387).		
(ii) Membership fees for those wishing to access the service (exploring whether it could be funded from direct payments, independent living / mobility payments);	(ii) An adult meets the eligibility criteria if their needs arise from or are related to a physical or mental impairment or illness; as a result of those needs the adult is unable to achieve two or more of the outcomes specified below and as a consequence there is, or is likely to be, a significant impact on the adult's well-being. The specified outcomes are— • managing and maintaining nutrition; • maintaining personal hygiene; • managing toilet needs; • being appropriately clothed; • being able to make use of the adult's home safely; • maintaining a habitable home environment; • developing and maintaining family or other personal relationships; • accessing and engaging in work, training, education or volunteering; • making use of necessary facilities or services in the local community including public transport, and recreational facilities or services; and • carrying out any caring responsibilities the adult has for a child.	(ii) Adult services currently have a service level agreement with HBC passenger transport to provide wheelchair accessible vehicles to people using its day services. The cost to support on average 61 people with a learning / physical disability is circa £240,000 per annum. The service has access to 5 vehicles and on average 14 spaces are allocated to people who are reliant on a wheelchair. If the buses were only utilised for wheelchair users this would equate to a daily cost of £40.18, however the bus is also used by people who do not require a wheelchair and has been set at £10 per day, or £18 per day for those who require a passenger assistant.	(ii) The SLA is still in place supporting people with a learning / physical disability. The journey and route times have improved since moving into the new Centre for Independent Living
(iii) Funding from Ward Member Budgets, the CCG and NTHFT to help towards the running	(iii) Head of Service to work in partnership with prospective organisations to pull together a bid to pump prime the running of a service.	(iii) Potential to pump prime a new service, cannot guarantee bid would be successful and would not create sustainability in the long term	(iii) DCLG bid submitted in January 2017 was unsuccessful

RECOMMENDATION	EXECUTIVE RESPONSE / PROPOSED ACTION^{+}	FINANCIAL / OTHER IMPLICATIONS	UPDATE
of the service; and (iv) The use of volunteer drivers	(iv)Meeting held with 'Supportive', which has 150 volunteer drivers in Durham. Subsidised service funded by public health and Durham CCG, provider is keen to expand into Hartlepool.	To develop a scheme in Hartlepool would require initial pump priming and a campaign to recruit and increase the number of volunteer drivers. The service in Durham is subsidised through Health and Children's services supporting Looked after Children and supervised family contact and Hospital and GP appointments	(iv) ‘Supportive’ continue to show an interest in further developing their volunteer driving scheme, at present they have 7 drivers from the Hartlepool area.
(b) That the potential of accessing / expanding existing Charity run schemes in the region be explored	RSVP (Retired and Senior Volunteer Programme) runs many driving schemes across the UK which provide free or low-cost door-to-door service for older or more vulnerable people NEAS - Ambulance Car Service Drivers (ACS) are volunteers who use their own vehicles to help with the transportation of patients to and from hospitals and clinics, thereby leaving ambulances free for emergencies and for patients too ill to travel by car. Over 150 volunteers helping out throughout the North East.	Cost is subject to individual requirements. Currently looking for any Ambulance Car Service volunteers in the Teesside, Darlington, Middlesbrough and Stockton-on-Tees areas and Hartlepool Volunteers are not paid for their time, however they do receive out of pocket expenses for their mileage.	Presentation to Committee on existing scheme supporting North Tees & Hartlepool NHS Trust
(c) (I) A request is made to provide a hospital shuttle bus	(I) Contact made with Brian Christelow, facilities manager at NT&HFT.	The service is funded by the Hartlepool and Stockton on Tees Clinical commissioning Group (CCG)	Presentation to Committee on the Hospital to Home service

RECOMMENDATION	EXECUTIVE RESPONSE / PROPOSED ACTION+	FINANCIAL / OTHER IMPLICATIONS	UPDATE
that is wheelchair accessible and can be used at all times including peak periods; and (ii) Explore whether this service could be included in a wider partnership scheme, such as the travel club	(i) Highlighted the recommendations in the report and proposal that a WAV be considered when procuring hospital transport (ii) Scheme already runs alongside the NEAS passenger transport service and volunteer ACS driver's scheme.		Presentation to Committee on the Hospital to Home service It is understood that the service is under review and looking to reduce the number of journeys between North Tees and Hartlepool Hospitals
(c) Examine whether a pre-bookable service could be put in place to provide transport to GP / hospital / dental appointments which is co-ordinated and booked by the health service, when appointments are made;	(d) Meeting held with Tracie Jacobs (H&ST CCG) and John Davison (CEO) of ' Supportive' who operate a Health Appointment Car Scheme (HACS) across Durham The provider is keen to expand into Stockton and Hartlepool.	Service is reliant on funding, and is subsidised by grants from Durham CCG and Durham County Council Further work required to identify the level of subsidy required.	There was previously a GP pre bookable transport service but the GPs gave notice on this as it was deemed to be too time consuming. Hospital Trusts are now able to make the bookings with NEAS online, for follow up outpatients' appointments and planned admissions. There are no investment opportunities at this

RECOMMENDATION	EXECUTIVE RESPONSE / PROPOSED ACTION$^+$	FINANCIAL / OTHER IMPLICATIONS	UPDATE
			time from the CCG, above and beyond the PTS service which is commissioned.
(d) In relation to the Patient Transport Service, ensure that the assessment criteria includes arrangements for carers to travel with patients and that this is implemented on all journeys when needed;	(e) Discussed and shared the report with CCG and NT&HFT	Awaiting feedback re future plans linked to conveyance.	There is a process to assess the requirement of an escort to accompany the patient on the journey. If a patient has a requirement for a carer, then this is considered and authorised where appropriate. The report shared previously shared, which includes the eligibility criteria is attached as **Appendix 2.**
(e) Explore the potential of any financially viable options for drivers and taxi companies to provide wheelchair accessible transport along with the potential of any available funding streams	(f) Discussion with local Transport Provider willing to provide a WAV. Provider has produced estimated costs of running a service. Provider agreed to await the outcome of further work to ascertain future demand.	(f) Initial discussions suggest an incentive of £2-£3 per journey may be sufficient to encourage Taxi Companies to provide WAV. Using the Severe Disablement Allowance SDA figure of 480 people, with an average of 6 journeys per week at £3, it would equate to around £449,000 in subsidies.	A private provider continues to provide a community travel club, having purchased a wheelchair accessible vehicle.

Good Health - Everybody's business

NHS

Hartlepool and Stockton-on-Tees
Clinical Commissioning Group

Introduction to Patient Transport Services

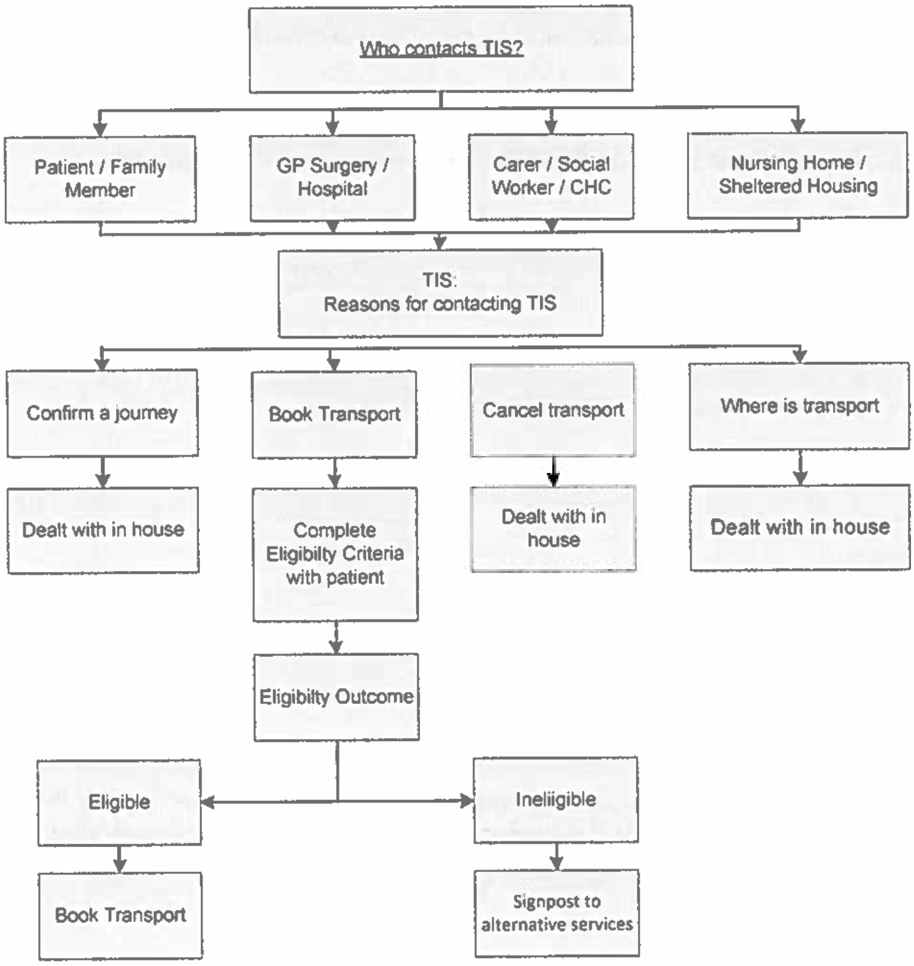
Patient Transport Services (PTS) provide pre-planned, non-emergency transport for patients travelling to a hospital or treatment centre. Transport is provided for patients who have a medical condition that would prevent them from travelling to their appointment by any other means, or who require the skills of an ambulance crew assistant during the journey.

In 2007 the Department of Health published guidance around appropriate use of NHS funded PTS. The purpose of this document was to provide criteria for establishing which patients were eligible for non-emergency patient transport services. The Teesside area was one of the first to implement the criteria. This was not consistent across the North East, which produced something of a post code lottery when it came to receiving PTS. Due to this and what was acknowledged to be an unsustainable increase in demand on local PTS provision, the north east Clinical Commissioning Groups (CCGs) collectively agreed in 2014 that it was time to implement a consistent, region wide criteria for determining patient eligibility.

The new criteria were implemented on the 20th October 2014 and since this date, the criteria have been asked for every booking.

Transport Information Service (TIS) deliver a Teeswide booking service for patients requesting NHS Patient Transport Services, and assess all patients contacting the service. A series of eligibility criterion is applied on each occasion a transport request is made to determine the suitability of patients requiring transport. Answers provided by the patient to the eligibility questions, establish their medical and mobility needs for the service. Transport is booked according to the outcome of the assessment.

Process Map



PTS Criteria

The following eligibility criteria are applied on each occasion a patient requests Patient Transport Services. A patient is required to score 31 points or over to become eligible for patient transport:

Eligibility Criteria for transport:

Is the patient's appointment for radiotherapy, chemotherapy or renal dialysis?

Yes	[50]
No	[0]

Is the patient registered blind?

Yes	[50]
No	[0]

Is the patient's journey for an inter-hospital transfer or hospital discharge?

Yes	[50]
No	[0]

Does treatment prevent the patient from making their own way home safely?

Yes	[50]
No	[0]

Is the patient able to use their own transport?

Yes	[0]
No	[0]

Can the patient drive comfortably to the hospital/clinic?

Yes	[Ineligible]
No	[0]

Is the patient able to use public transport to attend the hospital/clinic?

Yes	[Ineligible]
No	[0]

Does the patient have friends or family who could take them to the hospital/clinic?

Yes	[Ineligible]
No	[0]

At this time how does the patient normally travel to do their shopping and other general outings?

Done by someone else	[10]
Walk	[7]
Mobility Scooter	[7]
Community Transport	[2]
Other- Car, Taxi, Private Hire	[Ineligible]

At this time how does the patient move around their own home?

Confined to a bed	[31]
Only with a carer/parent	[18]
In a wheelchair	[7]
Using a Zimmer frame	[6]
Using a walking stick or crutches	[5]
Walking	[4]

At this time how far can the patient move outside of their home?

Nowhere	[31]
Into the street	[8]
Around the local area	[5]
To a main town	[0]

Given what you have told us about how the patient moves in and around their home, does the patient need support with getting from the hospital entrance to the relevant department/clinic?

Yes	[10]
No	[0]

Does the patient have any sight or hearing impairment which prevents them finding their own way?

Yes	[31]
No	[0]

Is the patient in regular contact with any mental health services?

Yes	[31]
No	[0]

Does the patient require Oxygen from our staff en route to hospital /clinic?

Yes	[31]
No	[0]

Eligibility for Escort: Score required 10

Is the patient 16 years or under?

Yes	[10]
No	[0]

At this time do any of the following apply when requesting escorts to travel with the patient?

Has a severe communication/learning difficulty?	[10]
Requires an escort from a nursing or residential home?	[10]
First referral cancer appointment?	[10]
[None of the above]	[0]

Patients who receive an ineligible decision, are provided with information for alternative means to get to their appointment. Contact numbers and information for voluntary services, shuttle buses, help with their travel costs and wheelchair accessible taxis, are provided to the patient.

NHS organisations work to ensure that users can get into hospital sights safely and conveniently. Consideration is given to the needs of people with disabilities, and Blue Badge holders, and disabled parking spaces are provided at the hospital sights.

Patients who are deemed ineligible for patient transport may also appeal against the decision. Appeals are actioned by the Patient Transport Appeals Team (PTAT) an independent service to maintain neutrality. During an appeal further information is gathered from the patient, and consideration is given to other contributing factors such as, the distance a patient is required to travel to their appointment, assistance requirements from the ambulance crew and how their medical condition prevents them from using other forms of transport to take them to their appointment. A patients GP practice may also be contacted with the patients' permission.

Below are the number of appeals and complaints

Hartlepool & Stockton CCG Appeals - 1 April 2015 to 31 March 2016	
Total number of Stockton patients requesting PTAT to appeal an ineligible decision	87
Total number of Hartlepool patients requesting PTAT to appeal an ineligible decision	98
Total number of appeals	185

Stockton Patient Appeals - 1 April 2015 to 31 March 2016			
Number of appeals decision overturned	Reason for overturning decision	Number of appeals decision upheld	Reason for upholding decision
61	Distance 43	26	Can Use Taxi 21
	Escorts 4		Escort 1
	Other 14		Cost Issue 2
			Other 2

Hartlepool Patient Appeals - 1 April 2015 to 31 March 2016			
Number of appeals decision overturned	Reason for overturning decision	Number of appeals decision upheld	Reason for upholding decision
66	Distance 36	32	Can Use Taxi 20
	Other 29		Escort 5
	Treatment 1		Cost Issue 1
			Other 6

TIS have not received any complaints regarding transport bookings for patients who have a disability during the period 1 April 2015 to 31 March 2016.

ADULT SERVICES COMMITTEE

12 July 2018

Report of: Director of Adult & Community Based Services

Subject: CARE QUALITY COMMISSION REPORT: DRIVING IMPROVEMENT

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1. TYPE OF DECISION/APPLICABLE CATEGORY

No decision required, for information.

2. PURPOSE OF REPORT

2.1 To provide the Adult Services Committee with information regarding the Care Quality Commission recent ‘Driving Improvement’ report which is attached as **Appendix 1**.

3. BACKGROUND

3.1 The Care Quality Commission’s Strategy for 2016 to 2021 ‘Shaping the Future’, was published in May 2016 and set out a vision for a more targeted, responsive and collaborative approach to regulation, so that more people get high-quality care.

3.2 A subsequent report was published in June 2017; ‘The state of adult social care services 2014 to 2017: Findings from CQC’s initial programme of comprehensive inspections in adult social care’. This report summarised the findings from inspections of adult social care over the three year period, what the sector could learn from those findings and how services have improved, while also considering how poor quality care is tackled and the next steps for regulation.

3.3 The 2017 report concluded that high-quality services exist in adult social care, which is positive and to be celebrated, but the variability in services means that too many people are experiencing care that does not meet the ‘Mum Test’. The report highlighted the difficulties that some providers experience in making improvements and also that some services have deteriorated following initial inspection which points to a fragility in the sector that needs to be addressed. The CQC wants more services to improve so that people's experiences of care continue to rise and for people to be aware that quality is the responsibility of everyone involved in adult social care.

4. DRIVING IMPROVEMENT

4.1 The June 2018 report 'Driving Improvement: Case studies from nine adult social care services' focuses on services which have made significant improvements and how services can be encouraged to improve.

4.2 To inform the report, the CQC identified nine services that had been rated as 'inadequate' and had made improvements to subsequently be rated as 'good'. For each of the services, CQC spoke to a range of people at each service. This included people who use services and their families, registered managers, providers and owners, care staff, administrative and other staff, commissioners and social workers.

4.3 The experiences of the services show that improvement in adult social care is possible. The nine case studies highlight some clear actions that other providers can use to help them learn and improve.

4.4 There are five key themes identified within the report:

Reaction to the initial inspection report
Most providers react to a report highlighting failures with shock, surprise and disappointment. But usually when people stand back and have time to reflect, they understand the failings.

For some staff the report can come as a relief, as they may have been struggling – doing their very best but unable to deliver the care they wanted to. For some, the report was a wake-up call; providers who allowed standards to slip, perhaps due to a range of pressures.

Leadership
The value of a good leader cannot be underestimated. In most of the providers we spoke to, a new manager had come into the service to deliver the improvements. They engage with staff, people who use services and their families and are open to suggestions but set parameters and take tough decisions where necessary.

Cultural change
Failing organisations tend to have cultures in which staff are afraid to speak out, don't feel they have a voice and are not listened to. Involving staff is one of the best ways to drive improvement.

Person-centred care
Typically, when a new manager took up the reins, they wanted to see care plans. And in most cases these were lacking in detail and did not show that the care being provided was person-centred. It is not possible to provide good care if the care staff do not understand the needs of the person being cared for.

Working with partners
Most of the services we feature received support to help them improve – mainly from the corporate provider, if there was one, or commissioning bodies.

5. LOCAL RESPONSE

5.1 There are no services in Hartlepool that are currently rated 'inadequate', although there are a number of services that are rated as 'requires improvement'.

5.2 As has been reported to Committee previously, there have been services in Hartlepool in the past that have been rated 'inadequate'. A number of these services were part of the same group and, in this instance, the four care homes for older people homes affected all ceased to operate following CQC enforcement action. Three other care homes for older people that were rated 'inadequate' have since made significant improvements and all three are currently rated 'good'. This evidences that the majority of local providers have reacted very proactively and positively when concerns have been raised and have been able to deliver major improvements, sometimes in a relatively short time. This is a positive indication of the commitment of those providers to delivering high quality care in Hartlepool, as well as a testament to the support provided to care homes by the Council and partners.

5.3 The Council, working with partners, and using the Better Care Fund and improved Better Care Fund, has demonstrated a significant commitment to driving the Care Quality Improvement Programme. As reported to Adult Services Committee previously, a range of initiatives have been implemented to support improvements including:

- Enhanced Pharmacy Support;
- Comprehensive Training & Education Programme;
- Capital investment in improving the care home environment;
- Quality Standards Framework, link officers and Focus Weeks;
- Support for new providers operating in Hartlepool; and
- Care Home Manager Forums that facilitate sharing of good practice.

5.4 The 'Driving Improvement' report will be shared with care home providers and managers in Hartlepool through regular forum meetings, so that the learning from these services is shared and can inform the support offered to providers locally where improvements are required.

6. RISK IMPLICATIONS

6.1 There are no risk implications associated with the publication of the CQC report.

7. FINANCIAL CONSIDERATIONS

7.1 There are no financial considerations associated with the publication of the CQC report.

8. LEGAL CONSIDERATIONS

8.1 There are no legal considerations identified.

9. CHILD AND FAMILY POVERTY CONSIDERATIONS

9.1 There are no identified child and family poverty considerations.

10. EQUALITY AND DIVERSITY CONSIDERATIONS

10.1 There are no equality and diversity considerations identified.

11. STAFF CONSIDERATIONS

11.1 There are no staff considerations identified.

12. ASSET MANAGEMENT CONSIDERATIONS

12.1 There are no asset management considerations identified.

13. RECOMMENDATION

13.1 It is recommended that the Adult Services Committee reviews the CQC consultation document and provides views on the draft response, to inform the final response that is submitted on behalf of Hartlepool Borough Council.

14. REASONS FOR RECOMMENDATIONS

14.1 The Adult Services Committee has oversight of adult social care services that are regulated by the CQC, and is committed to driving improvements in the quality of care delivered to local residents.

15. CONTACT OFFICER

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Care Quality Commission

Driving improvement

Case studies from nine adult social care services

JUNE 2018

Our purpose

The Care Quality Commission is the independent regulator of health and adult social care in England. We make sure that health and social care services provide people with safe, effective, compassionate, high-quality care and we encourage care services to improve.

Our role

- We register health and adult social care providers.
- We monitor and inspect services to see whether they are safe, effective, caring, responsive and well-led, and we publish what we find, including quality ratings.
- We use our legal powers to take action where we identify poor care.
- We speak independently, publishing regional and national views of the major quality issues in health and social care, and encouraging improvement by highlighting good practice.

Our values

Excellence – being a high-performing organisation

Caring – treating everyone with dignity and respect

Integrity – doing the right thing

Teamwork – learning from each other to be the best we can

Contents

Foreword

Andrea Sutcliffe
Chief Inspector of
Adult Social Care

We know that good adult social care services can transform people's lives and provide vital support at critical times.

But poor care can have a devastating impact, shattering people's quality of life; putting them at risk of harm and neglect; and undermining public confidence in the sector as a whole. That is why CQC concentrates on encouraging services to improve and takes action if they fail to do so.

Our work is guided by a simple principle – is this a service I would be happy for my Mum or anyone I love to use? If it is, that's fantastic; but if it's not good enough for my Mum, it's not good enough for anyone's Mum and we've got to do something about it. Lots of services have taken up that challenge and improved. We wanted to share some of their experiences to help others to improve too.

How does it feel to be rated as inadequate? What impact does it have? More importantly, what can you do to turn it around?

Staff and managers have told us that an inadequate rating can be devastating, with team morale plummeting and anxiety for people using services, their carers and families rising. Some may be tempted to complain and challenge; others to give up and leave. But the vast majority of services and their teams want to do something about it – to make sure they can meet the Mum Test and provide a service they'd be happy for anyone they love to receive.

That's who this improvement resource is for – the providers, managers and staff who want to learn and improve; the people they support who should expect consistently safe, compassionate, effective and high-quality care; and local commissioners who can help services get back on track. Who best to learn from but the people who have been there, done that and know what you are going through?

We visited nine services that had experienced an inadequate rating or enforcement action. We wanted to know how they reacted, what they did and what they learnt. We talked to people who use the services, their families and carers; chief executives, board directors, managers and staff; as well as other professionals. I am very grateful to everyone involved for their precious time, honesty and willingness to share their stories and insights.

Reading through these case studies, I was struck by two apparently contradictory thoughts – what needs to be done isn't rocket science, it's the basics of good leadership, good management and good care; but it's tough to get it right, to keep it going and there's a lot of hard work involved.

We all know these are challenging times for adult social care – pressure on resources; increasing demands and expectations; workforce shortages. In these circumstances, pulling yourself up from rock bottom is hard. We started out with a larger number of case studies but some of the services we intended to feature have struggled to sustain their improvements. It is a salutary lesson for us all. There can be no room for complacency.

But we know it can be done. We see 82% of services rated as inadequate improve, 42% to requires improvement and 40% to good. Getting the basics right is vital as the top tips from managers show – be clear about your vision, have an action plan to back it up and make sure it happens; seek support from others; communicate with everyone, your staff, the people using your service, their carers and families and your partners; and really focus on delivering truly person-centred care.

Time and again these case studies show that staff are key to achieving sustainable improvement – having enough staff; training and developing them to be capable and confident; listening and acting on their concerns; and making sure they are valued and fully involved.

What also shines through is the importance of leadership – having managers who know how to get things done; who can motivate and inspire their staff; who create an open and transparent culture; and who truly care about the people they support. We need to cherish and nurture our good leaders in adult social care.

Thank you to the team at CQC for researching and preparing these case studies. And thank you to everyone who agreed to take part. I hope their work helps people feel confident that improvement is possible.

I encourage everyone in adult social care to learn from their experience and make sure we can sustain good quality care for the benefit of all people using services, their families and carers. Nothing can be more important.

Andrea Sutcliffe,
Chief Inspector of Adult Social Care

> **"The vast majority of services want to make sure they provide a service they'd be happy for anyone they love to receive."**
>
> **Andrea Sutcliffe,**
> **Chief Inspector of Adult Social Care**

The services that we interviewed

> “Being encouraged to talk about things was a big change.”
>
> Rachel Kershaw, Senior Carer, The New Deanery Care Home

We interviewed a range of adult social care services on the basis that they had achieved a significant improvement on their rating. All nine services in this report have improved from a rating of inadequate (or equivalent) to a rating of good, some via a rating of requires improvement.

Service rating changes

Service	Location	Original rating	Current rating
Agincare UK Surrey (domiciliary care agency)	Woking, Surrey	**Inadequate**	**Good**
Collinson Court Care Home	Stoke On Trent, Staffordshire	**Inadequate**	**Good**
Eboney Home Care Limited	Consett, County Durham	**Inadequate**	**Good**
The Lawn Residential Care Home	Alton, Hampshire	**Inadequate**	**Good**
Leiston Old Abbey Residential Home	Leiston, Suffolk	**Inadequate**	**Good**
The New Deanery Care Home	Braintree, Essex	**Enforcement action***	**Good**
Ottley House Nursing Home	Shrewsbury, Shropshire	**Inadequate**	**Good**
The Potteries Care Home	Broadstone, Dorset	**Inadequate**	**Good**
St Cecilia’s Nursing Home	Bromley, Kent	**Inadequate****	**Good**

Source: CQC inspection reports

* Inspection before ratings scheme began

** First rated as requires improvement, before deteriorating to inadequate

For each service we interviewed a range of people, including people who use services and their families, registered managers, providers and owners, care staff, administrative and other staff, commissioners and social workers.

We used the following questions to interview providers and managers, and adapted them when interviewing people who use services, staff and others:

- What was your reaction to the service being rated as inadequate?
- How did you approach improvement?
- What support did you ask for and what support did you receive?
- What were the obstacles to improvement? How did you overcome them?
- Did the inspection report help you improve your service and outcomes for people?
- How did you involve staff and support them further in their work?
- How did you involve people, their families and carers and volunteers, who use the service?
- How did you involve and work with local partners?
- Could you give us some examples of tangible improvements?
- Could you give us some examples of improved outcomes for people?
- Looking back on the improvement journey, what have you learned, and is there anything you would do differently?
- What are you doing to ensure improvements are sustainable?
- What's next on your improvement journey?
- To summarise, what would you say are the top five actions you took that helped your service improve?

Acknowledgements

We would like to thank everyone involved in the production of this publication. This work would not have been possible without the support and time of the services who agreed to be case studies for improvement.

We are especially grateful to the staff, people who use services and members of the public who took the time to give their views on the improvement journey of their service.

Key themes

> “It’s the people who use services that come first. They should get the care plans they want for their care, not what we think.”
>
> Bev White,
> Manager, Agincare UK

Reaction to the initial inspection report

Most providers, and not just in the adult social care sector, react to a report highlighting failures with shock, surprise and disappointment. But usually when people stand back and have time to reflect, they understand the failings. As one care worker told us: “In the report we recognised the failings and could see the truth in what was said.”

For committed staff the report can come as a relief, as in some of our case studies staff were struggling – doing their very best but unable to deliver the care they wanted to. Some felt that it was “unfair” that they were overburdened while others did the bare minimum. Others felt “disgusted” at the standards, but felt unable to speak out. Several case studies highlight the impact that a rating of inadequate and report of poor practice can have on a service’s reputation, especially in close-knit communities. One care professional said, “It was really stressful getting shouted at in the street.”

For some, the report was a wake-up call; providers who had taken their eye off the ball, perhaps due to a range of pressures, and allowed standards to slip. Managers treated their inspection report as a “roadmap to improvement”, using the issues identified to create an action plan and work out priorities. Having a ‘we will get this right’ attitude was a key first step for improvement to happen.

Leadership

The value of a good leader cannot be underestimated. In most of the providers we spoke to, a new manager had come into the service to deliver the improvements. They engage with staff, people who use services and their families; they are open to suggestions but set parameters and take tough decisions where necessary. Staff and family members in some of our featured providers commented about a manager's door always being open.

Stability of leadership is also important. Staff at the Potteries Care Home had experienced a number of temporary managers covering for the home's manager who was on long-term sick leave, resulting in a lack of clarity about expectations. The appointment of a new permanent manager steadied the ship and enabled improvements to be made.

A leader doesn't necessarily have to come from a conventional care background. Ottley House Nursing Home's improvement journey started with the arrival of an ex-RAF nursing officer. Recruited as General Manager, Jamie Stubbs told us, "I would say I'm 80% leader and 20% manager. I've always wanted to give care staff so much confidence that they believe they are a leader." And that highlights another aspect of good leadership demonstrated in these case studies: the ability to develop good teams that can take responsibility for providing good care and for contributing to improvements.

For staff in some homes, just having a leader brought positive change. As one member of staff at St Cecilia's Nursing Home put it: "There was no one to manage us, there were no supervisions and no one to support us. This meant if we needed anything we had to call head office." Once an acting manager was appointed the member of staff felt more confident to raise issues.

Cultural change

Leadership and culture go hand in hand. It's the leader's job to shape the culture of an organisation. Failing organisations tend to have cultures in which staff are afraid to speak out, don't feel they have a voice and are not listened to. Involving staff is one of the best ways to drive improvement.

The Managing Director of the New Deanery Care Home described how the management culture under the previous owner had been "very controlling, very top down. Front line workers didn't have a voice, relatives didn't have a voice, the residents most certainly didn't have a voice. Nobody was speaking out because some of the poor care that had been going on had been witnessed by good people, but they hadn't felt able to speak up. The poor culture manifested itself in poor care."

And for staff the change in culture made a huge difference. According to one of the senior carers: "Being encouraged to talk about things was a big change. Now, if we make a mistake we are more than happy to speak up, knowing we won't be blamed or persecuted for it. We focus on what we have to do to stop it happening again. Before, we would have been hung out to dry."

Person-centred care

Typically, when a new manager took up the reins, they wanted to see care plans. And in most cases these were lacking in detail and did not demonstrate that the care being provided was person-centred. It is simply not possible to provide good care if the care staff do not understand the needs of the person being cared for.

"I've always wanted to give care staff so much confidence that they believe they are a leader."

Jamie Stubbs, General Manager, Ottley House Nursing Home

The experience of the new manager at Leiston Old Abbey Residential Home is played out in a number of our case studies. She started as though it was a new service and asked to see a care plan. It told her nothing about the person, so one of her first priorities was to improve plans to make sure they tell people's life story and how they like to spend their day.

There was a similar approach at Collinson Court Care Home, where we were told "we listened to the people here, we listened to the families. We completely rewrote all the support plans. Part of that rewrite was a bit of a life story sketch. We found out what people liked doing before they came to the home."

Plans need to be developed with the people using the service and their families. As the Manager of the domiciliary care agency Agincare UK put it: "It's the people who use services that come first. They should get the care plans they want for their care, not what we think."

Staffing

A range of issues to do with staffing contributed to the low rating in most of the providers featured in this publication. Too many providers were struggling along without having enough staff to deliver safe and effective services. It wasn't generally because the staff didn't care; it was because they didn't have the time to care as well as they should. And that put a great deal of stress on staff as well as putting people who used services at risk.

While not always an easy option or one taken lightly, some of our providers realised that they had to tackle the staff to service user ratio without delay. There was also an understanding that people who use services are best served by having a stable group of staff they know and who know them; bringing in agency staff to fill gaps on rotas was not desirable. "Having agency staff put quite a lot of stress on the permanent staff", said a healthcare assistant at The Potteries. The answer for some, then, was to take the hard decision to reduce the number of people using the service.

This is illustrated, for example, by Agincare UK, who told us that the key to improvement was to reduce the number of people using the service, handing some contracts back and not taking on any more self-funders. This took pressure off staff – "previously everything was very rushed for the care workers, now it is much more relaxed".

Commissioners should be mindful of providers' staffing needs. The manager at Collinson Court told us that "there were not enough staff commissioned to meet the needs of the people using the service…I had all the residents reassessed and actually got extra funding from the local authority."

While establishing a more stable staff foundation was important, tightening recruitment processes helped make sure that new staff coming in were suitable, and improved induction policies led to staff being better prepared.

Other features of poorly performing providers were a lack of training and staff appraisals: improving in these areas paid dividends. In one case study, the husband of someone using services has seen improved training "coming through" in the care his wife receives.

Working with partners

Most of the services we feature received support to help them improve – mainly from the corporate provider, if there was one, or commissioning bodies. The starting point was having a manager and staff who were willing to ask for support, were honest about the issues they faced, and were open and transparent about their plans for improvement.

For corporate providers, it is important to learn from issues. As Leonard Cheshire's Director of Quality said, "Our relatives group told us how disappointed they felt that they didn't see me or another director in the early days. Where we have services in that situation now, we meet with families and relatives so that we can have a very early discussion."

It is important for commissioners to play their part in improvement – as partners on the journey, not simply as someone with a contractual relationship. The manager of Leiston Old Abbey values the relationship she has with the Provider Support Advisor at her county council. Together they developed the action and support plans that led to improvement.

Building a community

Providers that are good and aspire to be outstanding look beyond their own walls and seek to be part of the local community. We saw great examples of providers opening their doors to local groups, working with local schools and bringing the families of the people who use their services through their doors. They also made sure they took people out into the community, to join in with local activities or simply to go shopping. The Lawn Care Home welcomes a mothers and toddlers group in every week. The daughter of one of the residents told us, "It's really great, my Mum loves little ones."

What does this mean for the adult social care system?

The sector-wide commitment to quality, Quality Matters, made clear that it isn't just what individual services do that makes a difference to quality – everyone has a responsibility, including staff, providers, commissioners, funders, regulators and national bodies all listening to the voice of people using services, their families and carers. Throughout these case studies you can see the truth of that. Managers talk about the support they had from their own organisation, local commissioners and NHS partners; how they involved their staff; the advice and encouragement they received from their CQC inspector; and how external agencies helped them to improve.

The message is obvious – leaving services to struggle alone is not an option. It takes a whole system effort to provide the necessary support, practical assistance and professional advice that will help managers make the necessary improvements. People using services, their families and carers have every right to expect this will happen so they can always rely upon safe, compassionate, effective, high-quality care wherever they are.

Agincare UK Surrey

January 2018

Rated as good

June 2017

Rated as requires improvement

January 2017

Rated as inadequate

Agincare UK Surrey is a domiciliary care agency that provides personal care to around 85 people in their own homes. An inspection in January 2017 resulted in a rating of inadequate. A follow-up inspection in June 2017 rated the services as requires improvement, and in January 2018 CQC rated the service as good.

Reaction to the initial inspection report

Vivian Singleton, who receives services from Agincare, says she agreed with the report: "I found the previous manager rude and the carer sometimes didn't turn up." For Bev White, who had recently joined the agency as Deputy Manager, CQC's report highlighted issues that she recognised but had not had the authority to improve. Following the inspection Bev was made Manager and was able to make progress on improvements.

According to Bev, some of the care workers were not surprised: "I met with them and explained [the report]. I had to be careful how I worded it. I didn't want to be dramatic. I had to be positive about the future and how they could help us. A couple left, but most responded positively."

Approach to improvement

CQC's report was clear that the agency did not have enough staff for the people they were contracted to look after. The key to improvement, she says, was therefore "to reduce the number of people using the service. Personally this was one of the worst things I had to do. I prioritised those with the highest needs [to stay with the agency] and prioritised those where the change would cause least stress [to leave]. I contacted social services and the change went quite smoothly.” The agency stopped taking on new business from self-funders. And while the numbers were being reduced, office staff (with the appropriate skills) helped out with care calls to make sure that all visits were covered.

At the same time, the council followed its policy of automatically removing any agency that was in special measures from its list of providers for new referrals.

Reducing the number of people using the service also took pressure off staff. “Previously”, says Bev, “everything was very rushed for the care workers, now it is much more relaxed.” That’s a change that went down well with Senior Carer Herminda Jones who says, “I never rush my customers. I had felt before that we were not able to do the job.”

Bev was also alarmed to see that on some weekends up to 20 calls had been missed. And there hadn’t been a system in place to record if calls had been missed, with the only ‘alert’ being if a client called the office. She explains, “I record everything – for example even if someone cancels a care call, I record it and the reasons.” Where an issue is noted, she puts “an outcome and update and attach any paperwork such as emails to other professionals. For example, when a care worker noted a client had swollen legs we called social services to determine if it was a safeguarding incident – everything is now documented. If you haven’t documented it, it hasn’t happened.”

For Divisional Director Luke Holmes, the main priority was to make sure clients were safe: “I spent a lot of time talking to clients and their families to ensure they were getting calls on time.”

The first CQC report noted that people did not always receive the medicines they needed. Bev says that medicine charts were not being audited properly. Charts were stored with people’s files and only audited 10 at a time. “Now I keep them together and audit every single plan every month. If there are any issues, if there are gaps or lack of a signature, I check who filled it in, call them in and do a reminder session.”

The agency also now has meetings to review learning from incidents, and staff are sent emails and texts that highlight the main learning points.

For Luke, the key to improvement was to make sure that the company’s policies and procedures were being followed. For example, notifications had not been made or issues not escalated as they should have been. He says, “We have changed company policy so that not making appropriate notifications to CQC is now treated as gross misconduct.”

Person-centred care

Bev wanted to make sure that care plans were comprehensive and, most importantly, truly reflected the care that people using the service wanted and needed. This was a massive and time consuming job. Bev took the lead, but involved senior care workers and consulted people who use services and their families. In two and a half months, all plans had been reviewed and revised.

Bev says, “When I met with people using the service and their families, I encouraged them to be open an honest about their needs. Some things can be embarrassing for people to discuss, but I tried to put their minds at rest.”

“I won’t take on a package unless I am 100% sure we can cover.”

Bev White, Manager

Care planning also involved assessing people’s home environment. On one assessment they found that someone had surrounded her hob with cook books, creating a potential fire hazard. The agency alerted the fire service, who visited the property to advise on fire safety.

Staff have welcomed the improved care plans. “Care plans have all been revised, which helps. They are more detailed and a lot more specific”, says Herminda. But even the best care plan isn’t the be-all and end-all for a service that puts the person at the heart of everything: “I ask my customers what they want first, then look at the care plan second”, says Herminda.

The changes have also been noted by Glynis Taylor, Social Care Development Co-ordinator, Surrey County Council: “They are now getting the basics right. Bev took a lot of time writing the plans. Now they are much more detailed, so care workers have a better understanding of their clients.”

Each care plan has a summary cover sheet and includes any special information, for example about any particular equipment the person may need.

Supporting staff

Easing the workload and getting meaningful care plans in place were the first steps in giving care staff better support. Previously staff might have been told to cover for others at short notice. “Now”, says Bev, “we don’t tell them; we ask them. It’s about knowing how to talk to people.” And when staff do need to cover, they can be confident they have the information they need about the client.

The earlier CQC report had noted that staff did not always receive the training they needed and few of them had regular supervisory meetings or appraisals.

Bev has made sure that all staff are up to date with their training. Everyone has a workbook that details training needs. In addition, if any gaps in knowledge are highlighted in other reports, Bev will contact the care worker to arrange a refresher. Herminda comments that “training is much better now – and I can do it from home on the computer.”

All staff now have regular appraisals and regular supervision. Bev is a believer in thanking staff and praising them for good work. She has also improved communications between staff and the office, with regular emails and staff meetings once a quarter.

Bev also took the view that getting the right atmosphere in the office would help staff feel part of a team and create an environment where they were comfortable to come in and talk about issues or concerns. Glynis Taylor noticed the difference: “When I used to visit before you didn’t see many carers in the office. There was a different atmosphere when Bev took over.”

Communication

Clients can now be sure that if they are due a visit from a care worker, the visit will take place. “I won’t take on a package unless I am 100% sure we can cover”, says Bev. “And won’t take on anyone unless we have assessed them.”

People are now sent rotas to confirm the visits for the following week and to tell them which care worker will see them. The agency tries to keep regular care staff as much as possible and this approach has created continuity for customers.

And as well as the scheduled visits, staff carry out welfare calls, phoning people to make sure they are OK.

Client satisfaction is checked through regular telephone surveys. Bev follows up any comments, feeding back to people on outcomes. For example if someone comments that a care worker was late, Bev finds out why and tells the person who raised the issue.

Working with partners

Early on in the improvement process, Bev had support from an Agincare nurse clinical lead and from other Agincare managers. They supported Bev in developing the action plans to carry out the required changes, and Agincare's internal auditors helped to monitor the plans.

There's good support from the corporate centre, says Bev, who adds that "Agincare is open and honest and shares learning at managers meetings." The company uses what happened as a case study to help train existing and new managers.

The local authority made clear it was open to requests for help, but Bev says she didn't call on this. However there was a regular 'Provider failure meeting' convened by the council that included the agency, CQC and local Quality Assurance managers. A council Quality Assurance manager goes in every two weeks to ensure that items in the action plan have been completed.

Looking forwards

Bev says that she is determined to keep the good rating and aim for outstanding: "We have the right dynamics in the office. People are not afraid to voice their opinion. I'll listen to the care workers if they think they could do something in a different way. I knew that making improvements would be hard work, but I was determined to do it. These people needed to have their care their way and I felt sorry for staff. If I had walked away they would have had nobody."

The final word goes to Vivian: "Now everyone is lovely. They do their job but we can have a laugh and a chat."

BEV'S TOP TIPS FOR DRIVING IMPROVEMENT

- ✓ **Communicate well with staff.**
- ✓ **Get care plans that are person-centred and have all the necessary information.**
- ✓ **Staff need training to put customers at ease.**
- ✓ **Understand risks and how to reduce them.**
- ✓ **Having the right number of staff to cover calls is essential.**

Answering the call

A mark of the improvement in the service is that Agincare is more responsive to the needs of people using the service, even if they fall outside a normal visit.

One example is when a relative called in distress as a person using the service who was bed-bound had become incontinent and needed to be moved. This was a task for more than one person, so Bev and the two office staff immediately switched the phones to the out of hours service and went to attend to the person. Bev's view was that they could not leave the person without help until the next scheduled visit.

Collinson Court Care Home

July 2016

Rated as good

January 2016

Notice of decision to close home issued

June 2015

Rated as inadequate

Collinson Court (part of Priory Adult Care) in Stoke-on-Trent provides accommodation and personal care for 10 people who have autism and behaviours that challenge.

We inspected the home in June 2015 and rated it as inadequate. We inspected again in January 2016 and found no improvements and issued a notice of decision to close the home. Following a meeting between CQC, the local authority, the provider and families of people who use the service, the provider was given time to make improvements to the service. A further inspection in July 2016 rated the home as good. The most recent inspection in July 2017 rated the service as good overall with an outstanding rating for the question, ‘Is the service responsive?’.

Reaction to the initial inspection report

Senior Support Worker Audrey Pepper was upset by the inadequate report: “I care so much about the people using services, I was just devastated.”

The report sent a wave of anxiety through the staff team at Collinson Court. Support Worker Kayley Hill explains that the inadequate report left staff unsure about the future of the home: “We thought we were going to get shut down.” Fellow Support Worker Bethany Mears adds that “The atmosphere wasn’t great because it was affecting a lot of people, and it sent staff morale down quite a bit. Families were quite upset and it made them a bit dubious about how their relatives were getting on here.”

“We heard that it could close and we were absolutely devastated” says parent Marguerite Brown. Her step-son has lived at Collinson Court since it was opened and all his adult life. "He'd been to quite a few places before he moved here, and when this first opened it was great for him."

For some parents the initial rating did not come as a shock. A parent, Carol Clarke, recognised the report's findings: "It could have been talking about our daughter; nothing at all was a surprise to us."

Approach to improvement

Michelle Widjaew started her role as Registered Manager of Collinson Court in January 2016, two days before the second inspection that resulted in a rating of inadequate. "I'm open and honest and say it how it is" says Michelle. "I told CQC that I could see the service had a lot of untapped potential but I was going to improve it for the people who lived here. The families and CQC had faith in me."

Michelle explains that she used CQC's inspection report, prioritising major breaches, to write an action plan. One area identified for improvement was staffing. "There weren't enough staff commissioned to meet the needs of the people using the service, and that resulted in frustrations and behaviours that challenged", says Michelle. "I had all the residents reassessed and actually got extra funding from the local authority to put the right staffing levels in place. This had a knock-on effect on activities, because we had the right number of staff to do them."

Cultural change

Resolving these issues has helped improve the service's culture, which in turn improved the quality of care. "Staff had just been told so much 'no you can't do that it's too risky' or 'no we haven't got enough staff'", says Deputy Manager Collette Salt. "But then we got the staff in place, took a positive behaviour support approach and suddenly their confidence grew. Now staff think 'yes we can go and do that now, even though there is a tiny risk' but it's a managed and therapeutic risk."

Michelle acknowledges that changing staff culture is challenging: "It was a real balance. There was a fear in staff that if they did something wrong the home would close. They knew the people who live here best so, with the help of the provider (Priory) and the local authority, I put the resource there so they could do things. It was about giving them the power back and making them enjoy coming to work." Michelle was keen to show that she and Collette were part of the team too, "We were doing nights, getting stuck in."

Families of people using the service recognise the impact Michelle's leadership has made. "The change was immediate, Michelle had an open door policy and listened to us as parents" says Nigel Brown. "We were pleased to hear the home was rated good. Michelle said 'now we've got that we're going to go for even better', and they're doing what they said. The determination from Michelle has trickled down and the staff are wonderful."

"Michelle led us the right way. We've got leadership now. If I've got a problem I know I can speak to Michelle and Collette. They're always there to listen, always there to help you."

Audrey Pepper, Senior Support Worker

Creative solutions

Staff thought creatively about how they could create a homely environment for people. One resident has behaviours that mean he damages things and because of this his bedroom had previously remained bare and undecorated. The home obtained anti-pick canvasses that he can't take off the wall, so now he has family photos up.

Person-centred care

The provider's Quality Improvement Lead, Chris Breen, who was part of the Priory's wider support team, explains "We listened to the people here, we listened to the families. We completely rewrote all the support plans. Part of that rewrite was a bit of a life story sketch. We found out what people liked doing before they came to the home, and we started to implement that again."

Some residents have difficulties communicating their needs and wishes. However, Activities Coordinator Bobby Aldous overcame this by "learning from the things that didn't suit; adapting, stopping, moving, changing, and speaking to parents again for a second opinion on things, then moving forward." Bobby describes the evaluation methods she uses: "Some places have numbers, on a scale of 1 to 10 on whether residents respond well. Well numbers don't mean anything to me or the person using the service. Were they happy? Could you visibly see they were happy? Did they give you an indication they were unhappy? How did they do that? It's a much more personal thing."

Carol Clarke describes the impact activities have had on her daughter: "Her face is beaming when she's doing some of them. You can see that she's really happy, whereas she was getting quite depressed before. She was just in her chair and she used to cry a lot for no reason."

Training was another area that was changed to meet the needs of people using the service. "This is an autism specialist service, but there was not any specialist autism training, so we arranged for staff to have a better understanding of the people they are looking after" says Michelle. "I am also completing a Master's degree in autism to strengthen my knowledge and then pass it on so we can further improve lives."

> **"Every single thing we do has got to be for people using the service because this is their home, we are coming into their home to support them. Anything we plan or think about doing, it needs to be in their best interests and what they want to do."**
>
> **Bethany Mears, Support Worker**

Building a community

"There is more of a community. A lot of the people using the service here had never really seen each other or interacted with each other, especially at social events" says parent Nigel. "Michelle changed that with the team and they had the first Collinson Court Christmas party." Group activities like this have improved his son's communication, "His speech is a lot better, he says a lot more and his knowledge has improved a lot."

People using the service now have greater access to the local community. "They are supported a lot better in their community. They are doing things that their families didn't think would ever be possible for them", says Bethany.

"I would like bigger things, because I know they are capable of bigger things", says Bobby. "One of the residents is an artist. He now enjoys producing art work, whereas before he would just destroy things. With persistence he has developed this skill, so we are planning a local art exhibition in the community for him to display his talent."

Families have noticed a big change in how they are involved. "Before I was made to feel like a second class citizen, I wasn't told anything" says Nigel Brown. "We get told now – they use technology to keep us informed, they send us photos of [our son] doing activities so we know what he's been up to. We don't worry if he's going to be alright now, we know that he is."

Working with partners

Michelle describes the relationship she has built with her local CQC inspector: "She has inspected us since I have been here, and has been involved right from the start. She had a job to do, but she would help where she could."

The home received ongoing support right across the system, from local commissioners and health professionals. "The psychiatrist would come quite often, not only to review the medications of the people who lived here but generally to see how things were going. He was a very big support to the home. All the community nurses upped their visits as well and visited weekly. It was nice to know that there were lots of people around who wanted it to work", recalls Michelle.

The local commissioner visited the home once a week and championed its improvement. According to Michelle, "She was amazing, she wanted it to succeed and supported me a lot. We also had the local safeguarding team, who used to come in once a week to help us, the support from them was really good."

Looking forwards

Collinson Court isn't standing still now it is rated as good. "What's next? More outstanding domains", says Michelle.

This ambition is shared by Chris Breen: "We've already got one outstanding area, we want to get that to all five domains."

"We're not settling for everything being okay" says Collette, "we want the best. We are focused on why we're here – the people we support – and we're striving for improvement all the time."

MICHELLE'S TOP TIPS FOR DRIVING IMPROVEMENT

- ✓ **Lead the team with a clear plan.**
- ✓ **Change the culture so staff are empowered to make changes based on their knowledge of the people they work with.**
- ✓ **Embed good practice within the staff team through training.**
- ✓ **Make sure the paperwork and processes are in place so you can monitor what's happening and use this to make improvements.**

Feeling part of the community

The home supports a lady who rips labels and stickers, who had never been shopping independently. They took her to Cheshire Oaks, which was holding their first ever autism evening. Activities Coordinator Bobby Aldous describes how "she shopped for two hours, trying on shoes, paying at the till, not even worrying about tickets or stickers on the till points. All of the staff there were in tears of joy", says Bobby.

Eboney Home Care Limited

June 2016

Rated as good

November 2015

Rated as inadequate

Eboney Home Care Limited, near Durham, is a small private agency providing personal care to around 70 people in their own homes. When CQC inspected in November 2015, it was providing care for 23 people.

The service was rated as inadequate, since there were issues that included care planning and records, recruitment and training. After a further unannounced inspection seven months later in June 2016, the service was rated as good.

Reaction to the initial inspection report

Eboney's Registered Manager, Cath Loates, was "gutted" by the rating of inadequate. Having built up the business since 2005, her business partner Sandra Harris agrees that it was "soul destroying". However, they recognise that they had "taken a step back" from the home care business, and that the report highlighted that this was not acceptable. They also think they had let their staff down. One member of the care staff, Sue Armstrong, says she felt "awful" about the inspection results, but that she was keen to stay and says "We worked our socks off to get things back on track." While they worked through the improvement plan, Eboney stopped taking on any new care packages, which had financial implications.

Communication

When the CQC report was published, Cath and Sandra organised a staff meeting to assure all staff that there was a plan of action and that, although it focused on the central office policies and procedures, this would benefit all staff, including those directly providing care services to people. Cath and Sandra moved back into the main office, so that they could communicate more easily with staff. They then went out on care visits with staff to find out their views on the situation. This engendered a spirit of teamwork, and enabled them to demonstrate the changes and reinforce company practice, such as signing to confirm that people's care plan updates are understood. They also rang people using services and their families and carers to update and reassure them.

Improved communication also benefits people using Eboney's services. David Eadie, who is the main carer for his wife Jean, says "Care staff tell us when they are coming, or the office tells us if they are running late. For example, if they've gone to a house and found someone needs an ambulance, they don't walk away. They wait until they arrive. We'd like to think they'd do the same if we were in the same boat!"

Person-centred care

A key improvement was around the quality of information Eboney held about people using services. By introducing a cloud-based system, staff were able to update records, including people's needs, easily and this would be shared in real time with those who need to know, including family and carers.

This has had a positive impact on people receiving care. David Eadie says the information staff have access to means "they are not starting from scratch. There's lots they know about Jean, and the care she's already received – like how to use the hoists and slings."

David explains that improvements at Eboney have meant that there is greater consistency in care staff, as before there had been "a bigger mixture". Having the same staff means that they know the little things that make a difference to Jean, like making sure she has a tissue in her sleeve, or seeing if she'd like to spray some of her favourite perfume.

> **"Care staff enjoy coming and Jean enjoys them coming. It also gives me a break each day."**
>
> **David Eadie, whose wife uses the service**

Supporting staff

Another key driver of improvement at Eboney Home Care Ltd was around staff training. The manager sought advice from a local training organisation, which recommended that they switch from three-yearly professional updates to annual updates, since there are constant changes in care practice. They implemented this and also moved their induction training from in-house, to a recognised, standard 12-week programme. One outcome of this focus on continual improvement is a greater awareness of safeguarding. Cath tells of an occasion when one of the care staff arrived in someone's home and was suspicious about a girl in the living room who said she was a carer. She rang the police who investigated immediately and found that the girl had stolen the person's bank card.

David Eadie has noticed the benefits of improved training, saying that it's "coming through" in the care his wife receives. He gives an example of how a rehabilitation nurse from the local hospital has given Eboney staff some

The little things that make a difference

Saghir Tahir's mother has used Eboney Home Care Ltd for around five years. He has noticed the improvement in the little things that staff notice – like watching what his mother eats and checking that the food in her cupboards is still in date.

Responsive care

Rebecca Winter, a social worker from the local authority who commissions care from Eboney, says their responsiveness can make a real difference to people. "We assessed a lady with dementia and asked Eboney if they could provide a mature, consistent care worker. From the first visit, they gave a good impression. The lady had been reluctant to bathe and her personal hygiene had been neglected. However, she took well to Eboney and she's now having a bath regularly. Her husband also built up a good relationship with the agency so he can now play golf knowing that his wife's needs are being met."

good practice training. For instance, they now know where to look for bed sores and how to prevent them. "My wife hasn't had a bed sore since she came out of hospital because they know how to check for them. Before, they wouldn't have noticed that, but something in their training has made them notice".

Working with partners

Cath and Sandra feel that, despite feeling "embarrassed" by the report findings, they were very well supported by local system partners (including the county council and NHS continuing care) who were positive and keen to focus on how to make improvements happen. The Strategic Commissioning Manager from the local council thought that the issues stemmed from the owners "overstretching" themselves, which meant they lost sight of the detail in their homecare service. However, unlike some other services, Eboney recognised the seriousness of the situation and were committed to improve.

Commissioners now value the relationship they have with Eboney's leadership. Rebecca Winter says "Cath is an approachable person. She's the face of the company and goes out to some of the initial meetings. Whichever member of staff you speak to, they seem to know all of the clients – it's the personal touch." Her colleague, Denise Williams agrees and adds, "I feel I can be absolutely honest with Eboney; you need to. The last thing we want is care packages breaking down."

Cath says that the CQC inspector was "professional all the way through" and gave them "loads of advice" such as referring to NICE guidance, making it clear what the steps to improvement were, what the deadlines were, and what the implications of failing to reach them would be. She highlights how important it was to be open and honest, so that they could establish a relationship of trust. Sandra describes the CQC inspection report as "the bible", since they were constantly able to refer back to the detail in it and fix the issues raised.

CATH AND SANDRA'S TOP FIVE TIPS FOR DRIVING IMPROVEMENT

- ✓ Go back to the drawing board.
- ✓ Be honest with staff, people using services and their families and carers.
- ✓ Staff are paramount: create a culture where they feel comfortable to talk.
- ✓ Communicate with other professionals.
- ✓ Be willing to accept help.

Cultural awareness training

As part of the enhanced training brought about as part of the post-inspection improvements, some care staff are receiving cultural awareness training so that they can feel more confident in supporting a Sikh woman to visit her local temple.

The Lawn Residential Care Home

March 2017

All questions rated as good

August 2016

Rated as good overall

January 2016

Rated as inadequate

The Lawn Residential Care Home in Hampshire provides accommodation for up to 31 older people, some of whom may also be living with dementia. It is run by the charity Friends of the Elderly. In January 2016, a CQC inspection resulted in a rating of inadequate. Hampshire County Council also raised concerns about safeguarding and the application of Deprivation of Liberty Safeguards.

In March 2016, all safeguarding concerns were closed by Hampshire County Council. After an inspection The Lawn was rated as good overall in August 2016, but with a requires improvement rating against the question of whether the service was effective. In March 2017, the effective question was also rated as good.

> **"I wasn't surprised. Things weren't the way they were supposed to be."**
>
> **Ron Wombell, resident**

Reaction to the initial inspection report

"I've known the home for over 12 years and my impression was of a great home with great staff" comments Cheryl Rothschild, Regional Director. "It was very upsetting", says Housekeeper Wendy Barnes, "It's always been such a good home and a great place to work."

The inspection happened at the same time as the provider, the charity Friends of the Elderly, was consulting with staff over revised terms and conditions of employment, which had caused some people to leave, and the home had seen a temporary rise in the use of agency staff. Patricia Chapman, whose father lives at The Lawn says "The fact these permanent staff left was very upsetting and it was unsettling for residents because they were seeing different faces every day."

These changes meant the inspection report was not a surprise to everyone. Healthcare Assistant, Nicole Avery, says "We had a lot of agency staff around that time and it was not running very smoothly."

Approach to improvement

After the initial shock of the rating, Friends of the Elderly was determined to make improvements. "There was a feeling of 'we can do this'", says Cheryl.

"Everybody pulled together and knew that we could put it right. We put an action plan together immediately after the inspection, using the summary the inspector gave us", says Rosemary Naylor, Director of Care Homes.

A core team made up of Cheryl, Rosemary and Sue Dorling, Friends of the Elderly's Clinical Lead, worked together on the action plan. "At the time, I was the Admiral Nurse for the charity and I was there every day. We set about doing all the practical things. We commissioned an independent lead to investigate the safeguarding concerns", says Cheryl.

Every support from the wider charity was offered to The Lawn, including the charity's Chief Executive and Chair of Trustees who met with residents and their families, alongside the operations team.

"If we needed help it was available", says Rosemary. She adds that the relationship with the CQC inspector was also very important. "It's hard to move anywhere without that relationship and support being in place."

"In the middle of all this, the Registered Manager decided to leave. But, we had already employed an Interim Manager for extra support, who stayed on until the improvements were made", explains Rosemary.

Relatives praised the organisation for how it managed the improvement process. "The impressive thing is that the improvements happened really smoothly", explains Michael Spoors, whose mother-in-law lives at the care home.

Prioritising safeguarding

"We wanted safeguarding to be the 'golden thread' throughout everything", says Rosemary. "It wasn't just 'this is a safeguarding process, this is how you report safeguarding', it needs to be linked into everything that we do for residents to keep them safe."

Concerns were raised in the CQC report that a person living under Deprivation of Liberty Safeguards was not being kept safe. In response, The Lawn fitted electronic door locks with alarms around the building which alerted staff each time an external door was opened. This quick response to the concerns had a negative impact on some of the other residents. "Others said they felt like they were hemmed in", explains Cheryl. The team at The Lawn listened to these concerns and adjusted the door entry and exit system so that people didn't feel shut in. Alternative solutions to safeguarding were also found: "We sourced a GPS tracker so the person living under Deprivation of Liberty Safeguards could go out when they

Working with SCIE

Friends of the Elderly commissioned support from the Social Care Institute for Excellence (SCIE) in addressing safeguarding concerns at The Lawn. They set up a Concerns Helpline facilitated by SCIE, which is anonymous, confidential and independent, and extends across the charity.

SCIE also completed a review of Friends of the Elderly's care planning, and supported a training programme that focused on the message that it is everyone in the organisation's business to be informed about how to report safeguarding, which extended to all staff and charity trustees.

SCIE also conducts an independent annual review of the charity's approach to safeguarding.

wanted to. The shift leader would be alerted if they went outside the perimeter of the home and we could see where they were in the building and outside."

A new Quality and Innovation Team was established at Friends of the Elderly to centrally monitor how safeguarding concerns were managed and to carry out a comprehensive programme of quality audits. Rosemary explains, "They do an audit of each home four times a year, tied in with the CQC key lines of enquiry." With improvements delivered and maintained at The Lawn, this team is now embedding the positive changes from lessons learnt across the charity's wider services.

Staffing

"Looking at the rotas, we sometimes had a majority of agency staff working who might not have worked here before – it wasn't safe", explains Cheryl. "We spoke to the agencies and told them we needed regular agency staff and they supplied us with a core group of five people who were the only ones we would use. Although they were agency staff, they felt like part of the team because they were with us every day. This bought The Lawn time to replenish its permanent staff, also supported by a small group of bank staff.

> **"Staff were on board from the very first meeting. The Chief Executive took it very seriously and got involved in driving through changes. We were very clear that we didn't want a blame culture – it was everybody's issue. Staff pulled out all the stops and stood by us because we were open with them and put them and residents at the centre of the changes. We couldn't have carried out all the improvements without them."**
>
> **Rosemary Naylor, Director of Care Homes**

The experience of having a high ratio of agency staff led The Lawn to introduce a new handover process. "We improved communication through the handover process", says Cheryl. "It's one of the most helpful changes we made; it's made a big difference to have a simplified handover with key information documented on one sheet of A4 for all staff to see", comments Nicole.

Communication

The management team and staff at the Lawn ensured that residents and relatives were involved in improvements from the beginning. This included holding meetings with them to share the inspection findings and outline what the action plan was. They were keen to talk to as many people as possible, offering individual meetings, including evening and weekends, where people were not able to attend the dates on offer.

"We had a meeting with all our other registered managers and went through The Lawn's CQC report with them in detail. A lot of our managers recognised the practices improved the delivery of care to residents", says Cheryl. Rosemary adds, "We have spread the knowledge and learning from

Learning lessons across the organisation

The lessons from The Lawn influenced Friends of the Elderly's approach to recruitment across the organisation. They set up a Business Development Team to look after recruitment for all of their homes which, according to Cheryl, "saves managers a lot of time."

> **"As we updated the action plan, we put all relevant documentation into an evidence file which provided proof of our actions", says Cheryl. "We wanted to be able to say we've done this and here's the proof and the audit trail with detail."**
>
> **Cheryl Rothschild, Regional Director**

this experience across all of the other Friends of the Elderly care homes and our community services".

Working with partners

Marie Moody, the Registered Manager is really keen to "bring the community into the home", particularly when it allows people from different generations to mix together. This is part of the charity's ambitious strategy to reposition its care homes as places which are open to, and deeply engaged with, the local community.

Currently, a mothers' and toddlers' group comes in every Thursday morning and residents are able to interact with the children or just sit and watch: "It's really great, my Mum loves little ones", says Gill Pears. Marie is looking to involve the local primary school in the care home more. The Year-2 class will be visiting The Lawn and the Year-6 class may be carrying out a gardening project on the grounds.

The Alton Men's Shed Club, which is open to both men and women, is working with The Lawn in a plan to have their shed in the home's grounds. Not only will this benefit the community, but the shed will be open to residents and will also provide support for the home – for example, making bird feeders.

Overall, The Lawn wants to ensure it embeds the care home as part of the community and not just "the care home down the road", but a "hub" in which the residents and the village of Alton can interact with each other, across the generations.

MARIE, ROSEMARY AND CHERYL'S TOP TIPS FOR DRIVING IMPROVEMENT

- ✓ **Be open and honest and get everyone on board with the journey. This includes having a no blame culture.**
- ✓ **Involve everybody in the changes that you make, including staff, volunteers, residents and relatives, and don't be afraid of asking for advice or think that you can do it all yourself.**
- ✓ **You can't fix it overnight, so focus on the long term. When you are solving issues always think about how the changes can be maintained.**
- ✓ **Ensure that people are looked at as individuals and not as a group. Although they are all living under one roof, residents are all different and people's wishes and aspirations will change over time.**
- ✓ **Ensure regular supervisions and training for staff.**
- ✓ **Ensure your audit and compliance checks are carried out and constantly dealt with.**
- ✓ **Work with the local Safeguarding Team and ensure your safeguarding processes are robust.**

Involving people in groups

Friends of the Elderly has involved two relatives and one person using services, who now sit on the Safeguarding Adults Sub-committee.

Several forums have been established in the home itself. For example, the residents' forum for food involves four residents who meet with the chef's team and the manager to discuss any changes needed. All residents can attend meal tasting sessions to have input into new menus. For example, when the home changed their coffee supplier, the residents were able to decide who the new supplier would be after tasting the options.

> **"The management team went through everything that was being done – they put our minds at rest. The steps to be taken were very well communicated."**
>
> Gill Pears, daughter of a resident.

Leiston Old Abbey Residential Home

March 2017

Rated as good

June 2016

Rated as requires improvement

September 2015

Rated as inadequate

Leiston Old Abbey Residential Home is a privately owned home in Suffolk that provides personal care for up to 40 older people, some of whom are living with dementia.

We inspected the home in September 2015 and rated it as inadequate. We inspected again in January 2016 but found no improvements and placed restrictions on any admissions and retained the inadequate rating. A further inspection in June 2016 rated the home as requires improvement. The most recent inspection in March 2017 resulted in an overall rating of good and good ratings across all our key questions.

Reaction to the initial inspection report

Owner Anil Agarwal was appalled and upset by the inadequate rating. He describes Leiston as “My baby and I let it down.” The initial inspection report highlighted to him that the home lacked competent management and he wasn’t receiving the right information to assure quality.

Karen Mays, a professional care worker for 25 years, recognised the poor rating, because staff weren’t working as a team. This situation was “Unfair, because some staff were working really hard, but others were lacking”, leading to low morale.

Diane Wythe, a fellow care worker, had reported some of the poor care that she had witnessed to a previous manager, but nothing was done. She told us that staff were poorly supported to maintain hygiene – for example, regularly running out of gloves.

One of the long-term residents, John Chatten-Berry says he “Didn’t feel very good when the low rating was awarded. Glad I stuck with it because it's got better." However, at the time, his concern was that he might be moved: "It worried me that I might have to end up in another home that's worse. My wife doesn't drive anymore so she wouldn't get to see me if I moved."

Approach to improvement

The inspection report gave the home a roadmap to improvement but it took time to make it happen. In the aftermath of the first inadequate rating, Anil employed a consultant to provide oversight and start a change in culture. He explains, "For this, the type of consultant is important, as most consultants look at details and lose sight of the bigger goal. For example he made us define the 'values' of the home."

It was the appointment of Sharon Morrison as Registered Manager, however, that really led to the home's stability and turnaround.

This was the third home that Sharon had been employed to bring about improvements, and she was able to bring her learning and experience to bear at Leiston. She started afresh, as though this were a new service. She started with the residents and asked to see a care plan. It told her nothing about the person, so one of her first priorities was to improve plans to make sure that they tell people's life stories and how they like to spend their day.

Jussie Cook, Contracts and Service Development Manager, at Ipswich & East Locality Adult and Community Services, recognises Sharon's systematic approach to improvement: "The Manager updated internal policies and procedures, taking advice where appropriate, implemented training, introduced regular 1:1 sessions with staff, and responded swiftly to requests for changes to customer's care provision following assessment by social work services." This has resulted in customer and professional feedback moving from 'very poor' to 'poor' to 'good' to 'excellent'.

For Tracy Emsden, improved training has helped her give better care to residents – "One of our residents has autism so I've just done five units on autism and that's given me a better understanding of him. That wouldn't have been available before."

Staffing

Another priority was to tackle staff shortages, absenteeism and a dependence on agency staff. Sharon called a meeting with all staff and asked them to comment on a new staff rota that she knew had worked well before. She emphasised the importance of issuing the rota with plenty of notice, giving people set shifts to build routine, and giving reasonable holiday cover. This enables staff to take responsibility over their shifts to ensure that residents are cared for well and consistently. Tracy Emsden, Senior Carer confirms that they were given good opportunity to comment on Sharon's ideas, and that regular team meetings boosted morale, because "before we weren't being listened to."

"We didn't have regular appraisals before, but now we have them with Sharon. It's an opportunity for Sharon to talk through improvements, but it also helps me feel good about myself, because I'm reliable."

Karen Mays, Carer

Communication

Manager Sharon takes a pragmatic approach to involving residents in improvements: "We do have residents meetings, but they don't like having big meetings, so I try to get them in a one-to-one conversation. I sit with them at lunch and ask them for their views on decorations, changes, activities."

John who lives at the home recognises this improved visibility, and it is clear that it has had a positive impact on his experience of care: "Before, you couldn't see the manager very often. Now you can. It made me feel more contented, having someone you recognise who will get things done. If you're not happy you just tell Sharon and she'll sort it out for you."

Sharon likes to lead by example, saying "I don't ask staff to do things that I couldn't do myself. I was a cook for a year and a half in a residential home so I can go in there and cook a dinner." This helped her implement new food hygiene systems, which moved the Food Standards Agency rating from 2 (improvement necessary) to 5 (very good).

Tracy, Senior Carer, appreciates the manager's new 'open door policy' and also that there are clear lines of communication: "I know that if I have a problem, I can always talk to Sharon. But I can also go to Anil too."

Person-centred care

Karen Mays says that addressing things like staffing and communications have seen improvements for residents, since staff are better able to encourage them to join in – "They're coming out of their rooms for lunch now. And families have said how people are looking better."

A lot of work has been done to improve the environment of the home. It has been decorated and refurnished, and a new games room has been added, as well as a conservatory so that residents can sit and watch the wildlife.

There is also now a much bigger emphasis on activities, and they're based on people's interests. One resident spent his life in farming, so the home organised a trip to a local farm. Many of the residents like music – a group that plays Vera Lynn music visits several times a month, and the residents are due to return the favour by going to one of their local concerts.

John sums up how he's supported to continue one of his hobbies, "In the home we do arts and crafts – drawing and painting. We've got someone in to help us, they didn't before. They understand that I'm colour blind and blind in my right eye, so I get the blues and greens and reds and browns mixed up."

Working with partners

Manager Sharon says you can take two different attitudes to external regulation and quality monitoring: you can shut your eyes and pretend it's not there, or you can welcome it with open arms, even if it tells you some uncomfortable truths. She very much subscribes to the latter, but she learned this through experience, as she has steered previous homes from failure to good quality. This meant she had built up a relationship with the local council – especially Anne Chapman, Provider Support Advisor, Suffolk

Making communication convenient

Leiston has a staff WhatsApp group that allows them to talk about any issues and seek support if there's a problem. Staff also use it to share photos and other less formal information, so it helps build the team. As well as saying thank you and sharing compliments, the manager also sends out important reminders, and she can use the app to check that everyone has seen them.

County Council – which turned into a very positive partnership. Sharon says, "Anne was in and out, involved from before I was involved. I opened up the doors to her and her staff. Everything they offered I took. The council should have a relationship with managers before things happen. You should see them for the help they are going to give, you're going to know them away!"

Anne recognises the importance of both sides being transparent and trusting each other. She says the rating of inadequate started the journey of change since there was nowhere else to go. The evidence in the inspection report helped Sharon to work out what needs to happen. Anne was able to support Sharon and Anil to:

- Create the action plan by going through the report to unpick the details and seek solutions.
- Recognise the issues and own the solutions.
- Develop a support plan, which included workshops for staff and audits.
- Keep channels of communication open, even now that the improvement journey is over.

Sharon has a similar view to the relationship with CQC. Once the improvements had started, when the inspector arrived, she says "I opened the door and said 'thank God you're here, come in' because I wanted to show them the changes we'd made."

Looking forwards

The priority for Anil and Sharon is to make Leiston 'the home of choice'. The home's reputation has been damaged, and they're finding it takes time to get the confidence of local people and commissioners back. The owner and manager are under no illusion that the home needs to be both on an upward trajectory of improvement, but also running as a viable business. With their leadership, the commitment of their caring staff, and the support of commissioners, they are confident that Leiston Old Abbey Residential Home can continue to provide great quality care long into the future.

SHARON'S TOP TIPS FOR DRIVING IMPROVEMENT

- **Get your improvement plan right.**
- **Consistency – having implemented routines, like infection control monitoring, two years ago, we keep these to help maintain improvement.**
- **Make training a priority.**
- **Feedback from residents and relatives is vital – it's them we're looking after and it's their home.**

> **My room's lovely – it was magnolia but they asked me what colour I would like and I said sunset because it's warmer. It's an orangey colour.**
>
> **John Chatten-Berry, resident**

The New Deanery Care Home

May 2016

Rated as good

November 2014

Rated as requires improvement

July 2014

Enforcement action

The New Deanery (part of Sonnet Care Homes (Essex) Limited) provides accommodation and personal care for up to 93 people in Braintree, Essex. In July 2014, a critical inspection report resulted in CQC taking enforcement action against the home – then called the Old Deanery.

A follow-up inspection in November 2014 awarded a rating of requires improvement. In May 2016, the New Deanery was rated as good overall, and outstanding against the question of whether the service is well-led.

In 2014, a TV documentary had revealed undercover filming of poor care that took place while the home was being managed by the previous provider. This led to very negative media attention.

Reaction to the initial inspection report

Senior Carer Rachel Kershaw says: "In the report we recognised the failings and could see the truth in what was said."

But a greater shock to staff had been the earlier documentary. Head Chef Paul Westall says: "I was disgusted by the behaviour and things that had happened here."

Following the negative publicity, the home and its staff felt a backlash from some in the local community. Senior Carer Charlotte Read says "It was really stressful getting shouted at in the street and in the shop." Brenda, a resident, comments on how upset the staff were: "Everyone was tarred with the same brush and it wasn't fair."

Approach to improvement

Julia Clinton, Chief Executive notes that CQC's reports had served as a reality check on the progress of improvement and helped to identify priorities. She was pleased that inspectors recognised there was a new team in place seeking to improve the home and gave them some extra time before a follow-up inspection. "CQC was very helpful. I knew the inspection manager was on the end of the phone. She was very calm and clear about expectations."

Cultural change

The revelations about the poor care and the impact of CQC's report convinced Julia that the top priority was to change the culture in the home. The management culture under the previous owners, says Julia, had been "Very controlling, very top down. Front line workers didn't have a voice, relatives didn't have a voice, the residents most certainly didn't have a voice. Nobody was speaking out because some of the poor care that had been going on had been witnessed by good people, but they hadn't felt able to speak up. The poor culture manifested itself in poor care."

Registered Manager, Jane Sadowski says that they wanted to create a "Great big no blame culture and move from a position where staff would say 'can we?' to one where they had the confidence to say 'we have done'."

Working with two managers, the directors agreed on three core values: Kindness, Comfort and Respect (KCR), which they supported with key principles and measures and summarised on one page to give to the service.

The next challenge was to get staff buy-in and start to change behaviours. The directors held briefing sessions that covered all 200 staff in the New Deanery and its associated nursing home, St Mary's Court.

"Some people were very keen, but many were just quite cynical – they'd heard it all before and took the view of 'we'll believe it when we see it' – they didn't mistrust us, they just didn't know us", says Julia. Some staff who were motivated by the changes volunteered to be part of a KCR workgroup to help get the values off the ground. KCR is now well-embedded, with monthly KCR awards open to staff and residents. One recently went to Brenda, a resident, for the work she did to help a care worker improve her English.

Communication

Rachel highlights the importance of the manager engaging with staff: "Before, we were despondent and disheartened. Jane came in and immediately had faith in us and gave us our confidence back and faith in our own ability. She wasn't saying 'you need to do this and this' – everyone had a view and we did it together."

There are weekly team meetings and formal communication with residents through a residents' forum and regular family meetings. John, a son of one

"Being encouraged to talk about things was a big change. Now, if we make a mistake we are more than happy to speak up, knowing we won't be blamed or persecuted for it. We focus on what we have to do to stop it happening again. Before, we would have been hung out to dry."

Rachel Kershaw, Senior Carer

of the residents, has attended the family meeting and says that "Things are taken on board and families are kept abreast of issues."

Informal communications have improved, too. "Every department is involved in everything", says Rachel. "You see the chef in residents' rooms chatting with them, seeing what they like. Housekeepers sit with residents and have a cup of tea and join our team meetings."

> **"There are no shortcuts to getting people to trust you. It takes time. Use lots of communication routes. Do what you can to earn trust. If someone tells you about something, do something about it. Go back, lead by example. Eventually people will start to get more confident in you."**
>
> **Jane Sadowski, Registered Manager**

Person-centred care

According to Senior Carer Rachel, "We went back to basics. We re-wrote all of our care plans so they were person-centred, not clinical, and focused on getting the care of residents right. If that's right, everything will follow. Care plans are now easy to read and families and residents are involved in the care planning."

> **"If residents ask for anything, we go above and beyond. If residents want a certain type of bread, colour of wallpaper or want to go out shopping, it happens. We will book them a taxi and there will always be a carer free to take them out. Before, we would have to ask about six managers if we could do that. We are now empowered to make decisions and take action."**
>
> **Rachel Kershaw, Senior Carer**

Brenda sums it up in a few words: "My needs and wishes are always at the front." Another resident, Dorothy, agrees: "They'll do anything for you. Carers always give you more time when they can."

> **"The emotional needs of residents is now a key focus. Before we had to be task orientated; now residents dictate their routine and what they would like to do, and we follow that."**
>
> **Rachel Kershaw, Senior Carer**

Staffing

To provide safe care, an early decision was taken to reduce the number of residents. This was a challenging process achieved by identifying residents who needed higher levels of either nursing or dementia care and then supporting them to move to other homes. This greatly improved the ratio of staff to residents and took some of the pressure off to enable changes to be made.

At the same time, the provider stopped using agency staff and introduced a much more robust recruitment and induction process. “We raised the bar and introduced the Judgment Index to check suitability to make sure we never again recruited someone who would be unkind to a resident – or if they were, someone would tell us”, says Julia.

Staff training was prioritised and the directors ran bespoke management training for front line leaders.

Looking forwards

Reverend Rod Reid, Priest in Charge of St Mary’s Church in Bocking says, “The home worked really hard to draw in the community. It opened its doors to the village, the school, nursery groups, and families. They centred the home in the village and made it part of the community.”

“It’s never job done when you are looking after vulnerable people”, says Julia. “We are constantly looking for ways to find out what people feel about services.” Senior Carer Rachel says “I’m proud of getting ‘outstanding’ for well-led. We are going to get that overall ‘outstanding’ – that’s our mission and ultimate goal. Residents are happy and well cared for and that’s all we want. This home is a happy place.”

JULIA AND JANE’S TOP TIPS FOR DRIVING IMPROVEMENT

- ✓ **Find a way to eliminate the gap between the board and the floor, so that people who lead the business reflect what’s going on at the front line.**
- ✓ **Be brave and make decisions about who isn’t coming on the journey.**
- ✓ **Make decisions quickly.**
- ✓ **Keep it simple.**
- ✓ **Communicate, communicate, repeat, repeat.**
- ✓ **Be prepared to work very, very hard…it will normalise but you need to put in the hours to start with.**

Increased choice

New Deanery resident Brenda highlights the way that the new Registered Manager addressed problems she was having with food by introducing more choice. “I didn’t like the food very much when I came here. It wasn’t until Jane came and saw I was losing so much weight that she changed things, so that if I want something that isn’t on the menu they get it for me.”

Chef Paul and his team have also developed a way of shaping pureed foods so they look like the food other residents are eating, making the meals much more appealing. They can represent 90 per cent of their menu, from green curry to mash and veg. It takes a lot of planning, but the outcome is that it encourages residents to eat more than they would otherwise.

Ottley House Nursing Home

August 2016

Rated as good

July 2015

Rated as requires improvement

December 2014

Rated as inadequate

Ottley House (part of Barchester Healthcare Homes Limited) in Shrewsbury provides accommodation on two separate units for up to 72 people who rely and depend on nursing and dementia care.

An inspection in December 2014 found the home to have ineffective leadership and it was rated as inadequate. In July 2015 CQC inspectors awarded an overall rating of requires improvement after finding action had been taken to improve the care and support people received.

By August 2016 Ottley House was able to demonstrate it was providing good care across all of CQC's five key questions and overall.

Reaction to the initial inspection report

Kat Lynch, Head Chef, has worked at Ottley House since 2011 and describes how it made her feel: "The papers got hold of it and there was awful stuff put on the internet – death threats and people saying they hoped we would die. I felt there were people here that shouldn't have been care staff. I didn't think we were ticking along brilliantly, but for myself and others that worked here, the report absolutely devastated us."

Around the time that the report was published, staff member, Adrian Morris, had given up his role as a Senior Carer because he didn't feel supported enough to do his job properly. Adrian explains, "Families were complaining all the time and justifiably so. We simply weren't delivering what we were supposed to be. We couldn't as we had no good continuity. There was 'Joe Blogs' coming in one day from one agency, 'Fred Smith' from another agency the next day, only one or two members of our own staff – and this is how we were expected to deal with it all of the time. It was a nightmare. Horrid."

David Morris, whose Mum is cared for at the home, adds "You only had to walk in and know the inspection would fail that day. Ottley was very chaotic at that time with management being out of their depth and you could tell staff morale was very low."

Approach to improvement

In January 2015 Ottley's improvement journey started with the arrival of Jamie Stubbs – an ex Flight Lieutenant Nursing Officer who had served for almost 20 years in the Royal Air Force.

Jamie was recruited as General Manager and is the first to admit coming to Ottley was about as far away from the hot and dusty environment of Basra, in the middle of the Iraq conflict, as you can get!

But he knew he had made the right choice: "What really interested me when I left the Air Force was, what can I do that can make a difference and challenge me? Ottley was something I felt I could make a difference in."

He adds, "While I'd never worked in a care home before, my belief is that as long as you can get the team and standards right then you can do anything. It didn't matter how bad the home was as my expertise lies in people and building teams – setting the standards, showing people what the standards are, providing clearly defined roles for everybody and bags of support."

Leadership

It's clear that Jamie's role has been integral in leading to a positive impact when it comes to the morale of staff and the quality of people's care at Ottley. "If I was to define my role, I would say I'm 80% leader and 20% manager", he says. "I've always wanted to give care staff so much confidence that they believe they are a leader – they can lead a shift. I'm not going to shout at them. I'm going to give them big thumbs up and buy them a bunch of flowers!"

He adds, "I had four clear objectives – 100% CQC compliance, 100% occupancy, zero agency and financial control of the home. But I couldn't do that on my own; I needed my Heads of Department. So there was a massive change programme going on with me saying, these are your departments, these are your budgets, this is your home, please take ownership of it. And do you know what? No-one let me down."

> **"There's a saying that to be a good leader you've got to have good followers. No. To be leader you've got to breed more leaders."**
>
> **Jamie Stubbs, Senior General Manager**

Staff at Ottley now look forward to coming to work which is down to the way that Ottley values their workforce. Jamie says, "We had staff here not believing in themselves. Rubbish. You can be who you want to be.

Communication on the frontline

When Jamie was working in Iraq he witnessed amazing transfers of care in the most difficult of environments: "My argument is, if gold standard care can happen at 30,000 feet in the air, when someone's care is passed over from one person to another, to another, to another – why can't it happen in this home, or any other home?"

Empowering staff to help 'steer the ship'

Staff were given a CQC report from an inadequate care home to see if there was any bad practice they could see in their work, as well as an outstanding report to see if there was anything that could be done at Ottley.

Care staff took over managers' meetings by giving presentations on how they thought they could "steer the ship" and then their changes were implemented.

The ultimate goal was for a Care Assistant to feel so empowered that if the Manager didn't come into work that day, they could go and sit in the Manager's chair and do their job for the day.

We've had five people now leave and go on to University. We've lost five members of staff, but we've won because they're off to get a degree and be a nurse and realise their dreams. They might come back to us, they might not do, but we've won."

Cultural change

Jamie's improvement drive was supported by Davina Mcloughlin (now Registered Manager) and Claire Williams (now Deputy Manager) who both joined Ottley in May 2015 to help with the challenge. Davina says, "Across the whole home it was about changing people's ways of work and there was lots of resistance to sort out at the beginning. It was completely broken so we had to restructure everything and start again."

Claire remembers it was the culture within the home that was the main obstacle: "With other managers having been and gone, there was real confusion. So we had to work on that – not only through putting clear structures, meetings, support, boundaries and expectations in place – but by gelling as a team on the floor. We got our uniforms on and were hands on so staff could see and believe for themselves that we weren't just talk – we really were with them."

Staffing

Referring to his first walk around at the home, Jamie says "It was like the 'Wild West' in here. You could see staff that really shouldn't have been here – poor dress sense and clearly not interested. But there were others who really loved the home, had been here a long time and wanted it right. I felt that through bad leadership the home had got to a state and I felt sorry for the staff who wanted it to be right."

One of the biggest challenges for Jamie was tackling the reliance and cost of agency staff: "The home was running on about 250 agency nursing hours a week and about 300 hours of care. So instantly you've not got a team at all. The key was to recruit the right staff as quickly as possible."

Jamie adds, "I was quite specific that we would use agency until we got the right people. Eventually we sorted out the recruitment and whittled it down until it was zero agency. Then we could really start to build a great team."

Adrian, Care Assistant, says, "We were sceptical to start with, but within a few months we could see it was working. Our own staff started walking through the door again thanks to the recruitment drive."

Person-centred care

Davina tackled the lack of proper systems, processes, procedures or audits being carried out in relation to people's individual care plans. As David Morris explains: "Before, my Mum's end of life care had been lost three times. I don't think they ever did a care plan. The whole attitude to procedures now is different. There's a structure in place and you know everything is running properly."

Jackie Clegg, Administrator, says, "There's now two folders of people's care plans for each unit that are checked twice a day. From checking the notes on nursing needs – to maintenance and housekeeping – everything is continually looked through and updated thoroughly.”

Kat Lynch explains that it’s everyone’s job to make sure that people using services are at the centre of everything they do: “I don’t just do the catering; I got Level 2 in Dementia Care Services and get involved with the activities too. On the Memory Lane Unit, Jackie and I now make memory boxes for people here and encourage the family to bring photos in.”

> **“There’s a lady here who is 98 and wrote a book about her life and gave me the section from 1939 to 1945 – I placed it onto a board and it’s now in the coffee lounge for everyone to see and celebrate. It’s fantastic for the residents, and anyone coming into the home, to see and read their stories like this.”**
>
> **Kat Lynch, Head Chef**

Looking forwards

Jamie says, “I want to push this service forward, and you’ve got to think creatively to do that. That isn’t necessarily about having good activities in Ottley, it’s about getting our residents out of the home to do good activities elsewhere in the community. To get the outstanding rating, you and everyone you work with has got to want it and you’ve got to want it so bad that it’s painful – I go to work every day with that mind-set.

JAMIE’S TOP TIPS FOR IMPROVEMENT

- **Having a clear vision of where you’re trying to get to is vital.**
- **You need high standards of discipline.**
- **Staff should understand their roles and responsibilities thoroughly.**
- **Support staff to be free thinkers and give them the opportunity to express their views and ideas.**
- **Take risks – never be frightened to let your staff make a decision. If it’s wrong, you can talk about it afterwards.**

The Potteries Care Home

January 2017

Rated as good

October 2015

Rated as requires improvement

March 2015

Rated as inadequate

The Potteries is a purpose built home for up to 80 people who require either nursing or personal care near Poole in Dorset. It is run by Care UK Community Partnerships Ltd.

The home is divided into three separate living suites. The ground floor is for people who maintain a degree of independence; the first floor is for people with dementia; and the third floor is for people who require nursing care.

We inspected the home in March 2015 and rated it as inadequate. A follow-up inspection in October 2015 moved the rating to requires improvement, and an inspection in January 2017 resulted in an overall rating of good and good ratings across all our key questions.

Reaction to the initial inspection report

As a new home, the Potteries had a difficult start. The closure of a nearby home resulted in more residents being admitted at a faster pace than had been expected (42 in less than seven weeks), and there had been instability due to a number of temporary managers covering for the home's manager who was on long-term sick leave.

> **"The first report was not unexpected. We knew bringing in as many people as we had to meant we wouldn't be spot on, but I had not expected it to be that bad."**
>
> **Alison Holloway, Business Administrator**

Michelle Stokes, who manages the dementia suite, says “the report was really upsetting because everyone worked so hard” but she recognised that the frequent changes in leadership had taken its toll.

Approach to improvement

Zita Turner led the work on improvement. She joined the Potteries as a Unit Manager from the nearby home that closed, but stepped up as Interim Manager and then successfully applied for the permanent role.

With her line Manager and Clinical Governance colleagues, Zita consolidated all of the issues raised in the CQC report into a service improvement plan. This plan was then followed to deliver, monitor improvement and measure sustainability and the actions that needed to be taken.

To support the improvement work, Care UK’s head office provided an operational support manager and other resources through its quality improvement and governance teams. The company also put a stop to new admissions while the home worked on improvement. While this helped by taking pressure of staff, it meant no additional income was available.

Zita developed the service improvement plan, which was shared with head office. This wasn’t done in isolation; she held a staff meeting where she told staff about the rating and asked for ideas from care staff. Zita also personally carried out all one-to-one staff appraisals to get feedback from everyone about what they thought had gone well and what had not gone well.

An early priority for Zita was to appoint a clinical lead to get to grips with some of the issues highlighted by CQC’s report, such as concerns about the management of medicines and medication, and focusing on training for nurses.

It was also, says Zita, “about forming good teams. We now have great leadership and have a whole-home approach, where everybody helps. Team leaders need to remain united, have a positive attitude and support staff.” Managers spend time helping out ‘on the floor’, which reassures staff “that managers understand what the job is”.

Cultural change

From the start, staff were encouraged to share their ideas about improvements. According to Michelle Stokes “Zita was asking how things should be done. She has an open door and she likes ideas.” Hayley Ansell echoes that: “Zita is really approachable. We are able to voice our concerns. She’s firm but fair.”

Staff feel more valued and there are monthly staff awards, where staff nominate colleagues. Managers recognise staff efforts in less formal ways, such as leaving a box of chocolates in a nurses’ station and arranging nights out.

The turning point

Given the instability that had affected the home’s performance, it was important at the start to bring staff together with clear leadership that involved staff and listened to them. But it wasn’t always plain sailing. At an early stage Zita and the new clinical lead organised a Sunday picnic in a local park for staff. They took food and games, but nobody came. However, they took some pictures of themselves, and put them on noticeboards in the home. “This was a turning point”, said Zita. “It showed staff that we were committed.” Soon after, they arranged a bowling evening and staff turned up in numbers.

YOPEY Befrienders

The Potteries has teamed up with local schools and YOPEY, the Young People of the Year charity, to help recruit about 60 students from local schools as ‘Befrienders’.

Residents look forward to the regular visits, and enjoy chatting with the students over tea and cake – often reminiscing about the residents’ younger years.

It’s an inclusive culture, with all staff encouraged to engage with residents. For example, members of the maintenance team help with lunches and Head Chef Sarah meets with families and residents regularly to discuss diets.

Staffing

The lack of continuity was evident in the reliance of the Potteries on agency staff. At one point, agency workers were covering 600 hours of care a week. Zita’s view, shared by many colleagues, was that it would be in the best interests of residents and staff to cease the reliance on agencies. Dementia Unit Manager, Michelle Stokes, emphasised the value of residents having care staff that they know: “They like familiar faces and that makes them more settled – and it makes our job easier.”

> **“Having agency staff put quite a lot of stress on permanent staff. Some were a pleasure to work with but they had different training and it felt like we were doing two jobs. Stress levels went right back down when staffing went up.”**
>
> **Hayley Ansell, Healthcare Assistant**

While there was an urgent need to bring in new permanent staff, they had to be the right staff: “We have a two-week induction period and we try to get new people to start together in the first week of the month. It’s two weeks before they even start to shadow and then they’ll spend two weeks shadowing shifts. The clinical lead did a lot of work to make sure ‘buddies’ were supporting new staff in the right way.” Zita meets all new starters and also meets them after they have been at The Potteries for a month: “It’s good to get feedback from fresh eyes.”

Training overall has been improved, with the Clinical Lead working with staff to raise awareness and improve practice in areas such as stroke care. Head Chef Sarah Beaumont said she is also able to attend training to help improve, for example, the choices she can offer people on restricted diets.

Communication

At the time the home was rated inadequate, internal communications were poor, with staff sometimes receiving mixed messages from managers. This has been addressed in a number of ways; for example, there is a short daily managers’ meeting at 10am, the notes from which are posted in staff rooms and fed back through regular team meetings.

Zita has a ‘flash’ meeting every day at 3pm to get updated on issues on each floor.

Karen Russell, whose mother is a resident in the home, and who works in the home as a volunteer to do arts and crafts with residents, says she is kept informed and asked for her views through family meetings. There are also resident meetings every two months.

Person-centred care

More rigour has been brought to care plans, making sure they are developed with residents and families and ensuring that they are followed. Alongside care plans, every resident now has a 'life history book' that includes memories and photos and a range of information about what they like to do. "The activities team needs to evidence how activities link to someone's life history and the information in the books are integrated with daily care", says Kimberley Devlin, Deputy Manager and Clinical Lead.

The home makes a special occasion of the monthly review of a resident's needs. When the review is due, the person becomes the 'Resident of the day'. During the day staff update the care plan and carry out medicines and risk assessment reviews; the Head Chef will spend time with the person chatting about meals and will also serve the resident a special meal of their choosing. In addition, staff check that the person has plenty of toiletries and clothing and the housekeeping staff carry out a deep clean of the person's room. Activities staff also arrange something that the person specifically wanted to do, or something based on the person's life history book.

Working with partners

The Potteries has a Customer Relations Manager, Rachel Wood, who works with external networks such as dementia support groups, memory clinics, the Women's Institute and church groups. Roz Hanson who, along with her husband Tony, runs a befriending service for older people, speaks highly of the way the Potteries has embraced their work. "Rachel has provided us with booklets on subjects, such as dementia, which we can give to our clients. She's told us we can bring people along to join in with activities in the home. There is a real buzz in the home and people always seem happy."

The Potteries has good links with the local authority – the home has a mixture of local authority and private paying residents. There are also now better links with local GPs and district nurses. The home ensures that GPs and district nurses are contacted just once a day with all relevant information. There is a weekly GP round.

ZITA'S TOP TIPS FOR DRIVING IMPROVEMENT

- ✓ **Good management with a robust leadership team is key.**
- ✓ **Empower your team and engage with staff.**
- ✓ **Support from head office can make a real difference.**
- ✓ **Balance being a good listener with tightening up on policies.**

St Cecilia's Nursing Home

January 2018

Rated as good

November 2016

Rated as requires improvement

May 2016

Enforcement action taken and rated as inadequate

St Cecilia's is a nursing home, providing a range of services for physically disabled adults in Bromley, Kent. Run by the charity Leonard Cheshire Disability, the home accommodates up to 30 people, most of whom have very complex needs.

In June 2015 the home was inspected and rated as requires improvement before deteriorating further and rated as inadequate in May 2016. But by January 2018 the home had turned things round significantly and was rated as providing good standards of care across all of CQC's five key questions and overall.

Reaction to the initial inspection report

Peter Keelan, Director of Quality, says "It was immensely frustrating as we'd had several inspections over a period of time all pointing in a particular direction, but we had not been able to get sufficient traction on the improvements. There was a lot of reflection and analysis at that point. It wasn't around a lack of understanding of issues, it was around a lack of our ability to grasp them and change them."

Families and staff were particularly saddened when St Cecilia's was given a poor rating, as it is described by many as a flagship service, known well in the local area. Sisters, Josephine McCoy and Anne McCoy, came here 14 years ago to oversee the care of their Mum. They say it initially felt like "winning the lottery" and they had a positive experience for many years. However, over time they became aware of difficulties and real issues with staffing. Anne says: "You're putting 100% trust in the place; you knew people were trying their best but the structure wasn't working and they didn't make us feel involved."

Josephine adds: "We could see the chaos, they were so short staffed. Our Mum is really vulnerable; she can't speak or communicate and needs an incredibly high level of nursing. We were worried that anything could be happening to her behind closed doors."

Roselyne Ncube, Clinical Nurse Lead, and the only permanent member of the nursing staff at the time, notes that even though she had only just started, she "wasn't really surprised" as the report outlined what she saw was happening in the service. "When I got to St Cecilia's I could tell things weren't in place, there wasn't much support and I really felt like leaving."

However, the benefit of its good reputation was that staff and families were totally invested in the improvement journey and were determined for the service to get back to its former glory. Jane Lightfoot notes St Cecilia's former "good reputation" was one of the reasons she decided to take up the position as Manager to lead the improvement work.

Approach to improvement

Jane's initial priorities were to organise the care plans, then refurbish the care offices, while trying to lift morale. Jane also set her sights on significantly improving recruitment and trying to establish a more permanent staff foundation. She says: "I wanted to look at recruitment because no service can run on its own. It's all about the team."

Pauline Fretwell, Head of Operations, confirms: "Morale was dire. The previous manager had been off sick for a while, the Deputy Manager had left and this all meant staff were at their wits end. Relatives also felt like they didn't have the ear of anyone to listen."

Communication

Peter Keelan notes that a key learning area was around engaging earlier with families and relatives. He says, "Our relatives group told us how disappointed they felt that they didn't see me or another director in the early days. They wanted confirmation that this wasn't going to be a short-term fix and that we were taking the problems seriously. We spent a lot of time at the service on improving things, but not enough time talking to and reassuring relatives and residents. Where we have services in that situation now, we meet with families and relatives at the draft inspection report stage so that we can have a very early discussion around what's going on and what's coming down the road. That way people are not finding out through rumour or via the local press."

It wasn't just communication with families and relatives that needed to improve. Pauline adds "Even on a staffing level, you found there'd been little communication – good or bad. They know there's been a CQC report but you need to go through it and explain why, what and how we're going to change things. Once they understand then generally they get on board. Otherwise, they don't feel valued."

She explains: "The response to call bells was very poor with too many delayed responses. So, we asked staff 'If you were sat in bed and had to

"We knew there was a lot to do but, as residents, we didn't quite know how much 'a lot' was. The fact that we didn't have enough staff to provide continuity of care didn't help and I was concerned the home would close. But I had faith that things would turn around. The ball began to start rolling when we got more staff to help with the paperwork, training and supervisions. Once you start seeing things happen and see things done, it inspires more confidence in the managers."

Margaret Keep, who has lived at St Cecilia's for over three years

> **"It's much easier to communicate and talk directly about any of our concerns now. The staff are all lovely to us."**
>
> Tom and Wyn Waller, parents of a resident

wait 20 minutes – how would you feel?' After a relatively short time, you could see response times getting quicker, with staff even starting to get competitive about it."

Good, open and clear communication was highlighted as a key factor that could help overcome a lot of the initial barriers to improvement. Physiotherapist Lynda Beadnall notes that just feeling like "you are being listened to" was crucial and "management talking to us and listening to us made us feel like we are part of a team" and the decision-making process.

Ralph Munro is Chair of the friends and families meeting. His wife has been cared for at the home for 10 years. Ralph notes that better communication was achieved through regular meetings every month, instead of every six to eight weeks as they had been. He says: "The meetings are not about being confrontational. It's about everyone – Jane, families, residents and volunteers – hearing the same answer at the same time and not feeling inhibited. Those who attend are more prepared to say what they feel now and I do notes afterwards."

Ensuring person-centred care

The first thing Jane did to help the service improve was to create more person-centred care plans. "I asked to look at a care plan, and said 'oh my goodness', because they weren't organised in the right way. I wanted to get new folders, and get all files audited and separated into support plans, health plans and DNR (do not resuscitate) information so this could be accessible to anyone who wants it."

Josephine and Anne's Mum can't speak, will need palliative care soon and is DNR. They explain the impact of their Mum's care plan not being in order: "One time, our mother was taken to hospital and shouldn't have been because of the DNR paperwork. The ambulance service had to take us to one side and tell us that the DNR was only a copy, not an original, which was really serious. They said 'we know we shouldn't take this woman to hospital but we have to'. Now, all of Mum's notes are in order, which is fantastic."

Leadership

St Cecilia's struggled most when there was a lack of leadership at the top. It was when there was a period of stability in management that the service could really start to improve.

Roselyne remembers when she first started her job: "There was no one to manage us, there were no supervisions and no one to support us. This meant that if we needed anything we had to call head office." At the time she felt like the home was just "troubleshooting".

Acting Manager, Pauline, was then appointed. Lynda notes that she now felt "listened to" and could raise "issues about needing more equipment", that she hadn't felt able to before.

The service began to further improve when Jane was permanently appointed. Roselyne comments: "When Jane came in she changed things around and started involving the nurses in how we were going to implement changes very quickly."

Supporting staff

The value of training and a move to having more permanent nursing staff that can provide better continuity of care has been instrumental in providing a higher quality service for residents at St Cecilia's.

Roselyne notes that when she first worked at the home, "There was no one to properly induct me, apart from head office. I had to find my way through everything alone as there was no one to manage us and there were no supervisions."

Lynda says the improved communication has made a significant difference to staff training and awareness. She points out the home now has a "visual guide of how to position a wheelchair" so that all staff members can do it the correct way.

Jane also recalls that when she came on the improvement journey a year ago one of her key goals was to try and retain more agency staff on a more permanent basis. She says: "I was able to recruit two previous agency staff to become permanent members of the nursing team."

Cultural change

With new leadership and a new nursing team, a change in culture at St Cecilia's soon followed. Margaret says: "The culture became more open. You used to have to raise the same issues at meetings. Now, things are different – there's no need for a topic from the last meeting to come up again as it's already been resolved."

Anne explains, "I can send an email on a Sunday afternoon and Jane will have replied by Monday morning with an answer to my question. If I get a response then I don't feel cross or anxious because I know I'm being listened to."

Josephine adds: "Before, if we came to management we were made to feel like we were in the wrong. We don't feel like that now. Jane never makes us feel like we're making a fuss."

Lynda emphasises that an open culture where everyone is continuously learning is key to a good service: "Before, I didn't want to come to work; there was a toxic culture of being too scared to ask questions. Now, it's a pleasure to come in and if there's a problem we can sort it out immediately."

JANE'S TOP TIPS FOR DRIVING IMPROVEMENT

- ✓ **Be a clear and visible leader.**
- ✓ **Listen and communicate.**
- ✓ **Remain tenacious. Improvement's not going to happen overnight, so don't give up.**
- ✓ **Don't put a rosy tint on the situation – be transparent.**

Being inducted into the whole service

Induction in the home has improved considerably. Staff go to all the departments to see how everyone is supporting the resident. Clinical Nurse Lead, Roselyne Ncube says "This means the care is much more holistic."

> **"When I first met Jane she gave me a hug and I just cried. She told me she'd put coconut oil on Mum's face every morning and I just felt, 'oh my God, this is the beginning of real change.' If we want to talk about anything, we go straight to Jane. She says 'come in, sit down, let me hear what the issues are.' She puts in so many hours. She's open, honest, loving, efficient, dedicated – she's just there."**
>
> Josephine McCoy, whose mother is a resident

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