My new home

Supporting people with an intellectual/learning disability and advancing dementia moving into a care home

Guidance for staff

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Contents

Introduction

This guidance was developed by Healthcare Improvement Scotland and the Care Inspectorate in collaboration with:

- Alzheimer Scotland
- Inverclyde Health and Social Care Partnership (HSCP)
- NHS Lothian
- Quarriers
- Scottish Government
- Thorntoun Estate Care Home, and
- University of Stirling.

This guidance is for staff and services involved in supporting people living with an intellectual/learning disability and advancing dementia and their carers. The guidance aims to ensure that, when and where required, transition to a care home is appropriate and provides the best outcomes for the person. It is anticipated that this guidance will support teams to identify priorities for improvement in their areas and inform service/quality improvement activities. More information about quality improvement can be found in the resources below. The principles and legislation in Scotland which supports this guidance can be found in the appendix. Information was gathered from:

- people with lived experience of a learning disability
- carers supporting someone with a learning disability
- care home staff, and
- health and social care staff who provide care and support for people with a learning disability and advancing dementia.

The terms intellectual disability and learning disability are often used interchangeably. In this document, we use the term learning disability.

Resources

Care Inspectorate: The Hub
hub.careinspectorate.com/how-we-support-improvement/improvement-support-section/

Healthcare Improvement Scotland
ihub
ihub.scot

NHS Education for Scotland
The Quality Improvement Zone (QI Zone)
learn.nes.nhs.scot/741/quality-improvement-zone

Context

In Scotland, within the Keys to Life strategy, people with a learning disability are described as having a significant, lifelong, condition that started before adulthood, which affected their development, and which means they need help to:

- understand information
- learn skills, and
- cope independently[1].

People with a learning disability are now living for longer and are therefore more likely to develop illnesses associated with age. Subsequently, they are at increased risk of dementia when compared to the population generally[2]. For people living with Down's syndrome, the risk is higher again[3].

- around 30% of people living with Down's syndrome who are in their 50's also experience Alzheimer's dementia[3]
- about 50% of people living with Down's syndrome in their 60's also experience Alzheimer's dementia[3]
- age-related dementia of all types is more common at earlier ages in people living with a learning disability than in the rest of the population (about 13% in the 60 to 65 year old age group compared with 1% in the general population)[2], and
- for those aged over 60 years the prevalence is estimated to be at two to three times greater in people with a learning disability[2].

By the time a person is living with the advanced stages of dementia, the illness may have impacted all areas of human ability. Memory, communication, understanding, thinking, judgement, planning, learning and physical functioning may be severely affected. People can live with advanced dementia for many years, although recognising the advancing stage of dementia in people with a learning disability is often more complex.

Why this guidance is needed

There are a number of different places that adults with a learning disability call home in Scotland. This includes:

- rented from a housing association
- supported accommodation which may be shared
- care and cluster (a single person flat alongside other flats occupied by people with a learning disability all receiving staff support)
- a home they own

- a home they privately rent
- shared housing with family or friends, or
- a care home.

Care home definition

The Public Services Reform (Scotland) Act 2010 provides the following definition of a care home.

"A '**care home service**' is a service which provides accommodation, together with nursing, personal care or personal support, for persons by reason of their vulnerability or need; but the expression does not include:

a) a hospital

b) a public, independent, or grant-aided school, or

c) a service excepted from this definition by regulations[4]."

In the first instance, people should be supported to remain in their current home as their dementia advances if this is their preference. However, there are occasions when this is no longer practical, safe or indeed desired by the person and their family. For some, the home environment may not adequately meet their needs. For example, this might be due to:

- the need for waking night staff
- staff or family not having the knowledge and skills required to support the person's needs, or
- the person's home not being able to be adapted to accommodate their changing needs.

This guidance focuses on people with a learning disability and advancing dementia who are moving to a care home because their needs have increased and can no longer be met in their own home. This guidance aims to enhance the appropriate care and support of people living with a learning disability and advancing dementia before, during and after a move to a care home should this be the most appropriate option after a review of all options.

The choice and reason for a move should be carefully reviewed. A decision to move to a care home should not be solely based on cost or other service driven reasons. For example, if someone is unable to navigate stairs, an upstairs room in a care home is not appropriate and may restrict outdoor access. Similarly, if waking night staff were previously required, the care home may be unable to provide the same therapeutic environment at night.

A decision to move into a care home should only be made after all other options to enable the person to remain at home have been explored, and the person with a learning disability has been supported to engage in this process using accessible and person centred communication methods where appropriate.

A housing option approach, as recommended by the Scottish Commission for Learning Disabilities (2017)[5], should ensure people receive advice that focuses not only on accommodation, but also on their health and financial situation, thus taking a holistic and person centred approach. Where appropriate, moves must be in accordance with the Adults with Incapacity (Scotland) Act (2000). Where a person does not have the capacity to decide or agree to moving to a care home, a welfare attorney or guardian must give consent, in line with the powers granted[6]. Principles of The Keys to Life should be followed at all times to ensure that people with a learning disability continue to have a healthy life, choice and control, independence and active citizenship[1]. People must have access to independent advocacy to ensure their wishes and choices are central to decision making about their future care and support.

Care homes for older people may be reluctant to admit people living with a learning disability and dementia. Concerns may include:

- staff not having the confidence, knowledge and skills to support someone with a learning disability
- questions around whether the individual will ‘fit in’ to the care home, and their integration with other people living there, and
- the individual’s specific needs not complying with the conditions of the care home’s registration, with changes and adaptations potentially required.

Some older people with a learning disability may have spent many years in large institutional settings with the challenges and limitations this brings including; institutionalisation, limited opportunities to build lasting relationships, limited privacy, and limited opportunity for any sort of 'family' life. Recent years have witnessed the growth of community-based support since the closure of large institutions. This includes shared accommodation on a smaller scale and home-based support. People with a learning disability talk of their fear of returning to larger settings as a result of previous negative experiences[7].

Consideration needs to be given to the fears of people who may view a large and communal setting as a backward step.

Ensuring a person centred approach

My care home will ensure a person centred approach is taken to decision making and care planning.

The person with a learning disability and dementia should be at the centre of any decision making. Where the person lacks capacity to make decisions, the principles of the Adults with Incapacity Act (Scotland) (2000) must be followed. This includes using appropriate communication support to ensure the person's rights, will and preferences are heard and respected[6].

Decisions at the point of transition to a care home should not be made on the basis of disability (or any other protected characteristic). Ideally, decisions about the future should be anticipatory where the person with a learning disability and their carers talk about what matters most when making plans for care in the future. This information should be documented in an anticipatory care plan (ACP)[8].

A personal outcomes approach should acknowledge individual strengths and work towards establishing a shared sense of purpose to which everyone can contribute, including the person, their family, carers, services and other community resources. This should aim to achieve the outcomes for the person living with a learning disability and dementia based on the principles listed below.

Overview of a person centred approach

Where I live

Where possible, I should be able to stay in my own home if that is what I want. Where I have to move, these moves should be kept to a minimum. If a crisis or emergency arises, appropriate support should be available close to my current home. I would like a choice about where I live and who I live with. Please do not assume I want to live with other people who have a learning disability. Ask me.

Overview of a person centred approach

The care I experience

My care should be person centred and respect my human rights. The focus should be on me as a person and not on the labels of my conditions. The staff that support me must understand how to care for someone with a learning disability living with dementia.

My care should be consistent with the Health and Social Care Standards.

A strengths-based approach

When sharing my needs with others, there should be a strengths-based approach – share what I can do, as well as where I need help and support.

Positive engagement

Engagement with me and those important to me should have positive outcomes. For example, offer opportunities to build and maintain relationships through regular interaction and communication. I should be supported to stay in contact with the people who are important to me.

A human rights based approach

According to the Scottish Human Rights Commission (SHRC), a human rights based approach is about empowering people to know and claim their rights[9].

The PANEL principles are one way of breaking down what a human rights based approach means in practice. PANEL stands for Participation, Accountability, Non-Discrimination and Equality, Empowerment and Legality. This includes the right to a diagnosis of dementia, having access to support after a diagnosis of dementia and ongoing support as appropriate[10]. The care that I receive is based on lived experience but also fits with policy, legislation and strategy.

My family life

My right to a family life is a fundamental human right and needs to include facilitation of contact with my family and people who are close to me.

Overview of a person centred approach

Timely discussions

Timely discussions should take place as part of support. There should be regular meetings focusing on what is important to me, my family and friends. My friends and I should still be able to see each other. We may need extra help to do this.

I should be supported to actively contribute to these discussions, using appropriate communication tools and approaches to facilitate my understanding as well as my ability to express my views.

Anticipatory care planning (ACP)

My care planning should be anticipatory where I talk about what matters most when making plans for my care in the future rather than waiting until things go wrong. If I have to move on, I and/or my family should be involved in making the decision. Information from my ACP should be shared with relevant people including my GP. I can bring my care plan with me.

ACP should begin early enough to enable informed discussions and making decisions[8].

Effective communication

There is a detailed description of how best to communicate with me, so that all staff who support me know how to engage and interact with me.

You should communicate with me using tools and approaches that work for me. This might include symbols, pictures or photos. I may have a communication passport to support me to make choices and decisions. Approaches such as "Talking Mats," should be explored. You should ensure that I am supported by a speech and language therapist to maximise my communication opportunities.

Meaningful and purposeful engagement should be an integral part of my day. Staff will create opportunities, relationships and environments that make me want to communicate.

There should be a "transition plan" to support my transition into my new home which helps me to prepare for my new environment. I can get to know staff and they can get to know me. They will know and understand my important routines, preferences and wishes. They will understand my communication needs before our first meeting.

Listed below are resources which support a person centred approach.

Resources

Alzheimer Scotland
Getting to know me
www.alzscot.org/sites/default/files/images/0002/7225/Getting_to_know_me_form_-_editable.pdf

Care Inspectorate
Personal planning guides for providers; Adults
hub.careinspectorate.com/how-we-support-improvement/care-inspectorate-programmes-and-publications/personal-planning-guides-for-providers/

Healthcare Improvement Scotland
Anticipatory Care Planning
ihub.scot/project-toolkits/anticipatory-care-planning-toolkit/anticipatory-care-planning-toolkit/

Learning Disability and Dementia
Jenny's diary
www.learningdisabilityanddementia.org/jennys-diary.html

Scottish Human Rights Commission
Human Rights Based Approach
www.scottishhumanrights.com/projects-and-programmes/human-rights-based-approach/

Royal College of Speech and Language Therapists
Five good communication standards
www.rcslt.org/wp-content/uploads/media/Project/RCSLT/good-comm-standards.pdf

The Learning Exchange
Talking Points: personal outcomes approach – practical guide
lx.iriss.org.uk/content/talking-points-personal-outcomes-approach-practical-guide

Together In Dementia Everyday
Restoring Relationships: The Recovery of Love, Connection and Family
www.tide.uk.net/restoring-relationships/

Knowledge, skills and training

My care home will ensure the staff who support me have the appropriate knowledge, skills and training.

The experience of living with advancing dementia will be unique to each person, just as the experience of having a learning disability is also unique. For this reason, staff working in care homes will require knowledge of how both dementia and a learning disability impacts on people and how to support their needs.

People living with a learning disability generally develop dementia at similar ages to people in the general population. However, people with Down's syndrome may develop dementia in their 40's and 50's. This means they may be up to 50 years younger than some of the other people living in the care home.

People living with a learning disability may have associated health conditions and comorbidities. People will require ongoing support to monitor and maintain their health and wellbeing. However, people's health and care needs will change as their condition progresses. This is similar to people living with dementia who do not have a learning disability. However, people living with Down's syndrome and dementia may experience late onset seizures. Ongoing learning and development are essential elements of quality assurance in all settings. Training needs will vary between establishments. In Scotland there is an expectation that care home staff receive dementia training at the skilled level of the Promoting Excellence Framework[11]. However, not all staff will have received training on, or information about, learning disability.

The Promoting Excellence Framework does not specifically address issues affecting people with a learning disability, however much of the guidance is transferrable. Staff may need additional training and guidance in order to support people living with a learning disability.

To help inform this guidance, a learning needs analysis (LNA) was conducted with a sample of care homes in one HSCP. This helped provide information about training care home staff identified as beneficial. Care home providers were encouraged to adopt this approach to evaluate staff's current understanding. Our LNA informed the template below, and identified gaps in knowledge.

Providers who complete an LNA are able to act proactively in their support and planning. When a care home does not currently have residents living with a learning disability, an LNA will identify learning and knowledge gaps that may enable training to take place.

Topic	Is this a training need for you/your care home? Please indicate yes or no	Add a priority number to each topic where your response is yes 1 (most important), 2, 3 etc
Supporting people living with a learning disability		
Supporting people living with dementia		
Learning disability and dementia		
Supporting people living with advanced dementia		
Palliative care		
End of life care		
Anticipatory care planning		
Supporting people who experience difficulties eating, drinking		
Supporting people's changing communication needs		
Please add your own topics below, or any specific areas that may be included in the topics above		
Mental health training		
Talking Mats		

Topic	Is this a training need for you/your care home? Please indicate yes or no	Add a priority number to each topic where your response is yes 1 (most important), 2, 3 etc
Autism awareness		
Dementia passport		
Getting to Know Me		

We acknowledge that funding for training may be limited in some instances; however, there are sources of good information on-line which we have included below. It may also be possible to ask locally if there are any opportunities for bespoke in-house training provided by professionals from the HSCP. It is important to note as stated above that the Promoting Excellence Framework is a free resource, which services should use.

Resources

Care Inspectorate
The Hub
hub.careinspectorate.com

Dementia Services Development Centre
www.dementia.stir.ac.uk/training-events

Learning (Intellectual) Disability and Dementia
www.learningdisabilityanddementia.org

NHS Education for Scotland in partnership with Scottish Government
Promoting Excellence 2021: A framework for all health and social services staff working with people with dementia, their families and carers
www.gov.scot/publications/promoting-excellence-2021-framework-health-social-services-staff-working-people-dementia-families-carers/

Resources

Scottish Commission for People with Learning Disabilities
www.scld.org.uk

Scottish Learning Disabilities Observatory
www.sldo.ac.uk

Specialist support and multiagency collaboration

My care home will have access to specialist support and multiagency collaboration.

To support the placement of an individual with a learning disability and advancing dementia into a care home, collaboration between services is required. This can be:

- before care home placement
- during the transition from community setting to the care home placement, and
- following admission to care home through provision of training, transfer of support and review of the placement.

Interservice collaboration before care home placement

Prior to a care home placement request, a full and comprehensive assessment of the person's care and support needs must be carried out by relevant professionals in the HSCP. This should be carried out in collaboration with the person and their carers. To obtain a true account of their care and support needs, all agencies who are currently involved should come together to provide this information. This list is not exhaustive but may include where relevant:

- GP
- social work
- learning disability team including:
    - nursing staff
    - occupational therapy
    - psychiatry
    - psychology
    - physiotherapy
    - dietetics
    - speech and language therapy
- care provider

- independent advocacy and
- family and/or carer.

It is recommended that an information template is used, such as the single shared assessment, to capture and summarise ongoing care and support needs from all supports and services who are involved. A template like the hospital passport could be used[12]. The passport is used for people with a learning disability when they are admitted to hospital. The passport includes information that hospital staff must know about the individual, things that are important to them, their likes and dislikes and assists hospital staff to make reasonable adjustments in the provision of safe and effective care. It also contains key information about the person’s communication, treatment and diagnosis, including the type of dementia if this is known[12].

This is also transferrable to other care settings including care homes. If completed from the outset, involving all supports and services, for the individual, this will ensure care home providers have a comprehensive understanding of the individual’s current and future care and support needs. This should include a positive behaviour support plan if appropriate. This will provide information and guidance to prevent and support people experiencing stress and distress. Care home providers can then make an informed care home placement decision. Another resource that could be used is the Anticipatory Care Calendar (ACC)[13]. The ACC aids the recording and communication of health issues. The ACC can be used in any social care setting supporting people living with a learning disability and dementia. It assesses health on a daily basis and alerts staff to changes in a person’s health status. This resource could be used while being supported in the community and be included as part of the transition plan and ongoing care and support following care home placement. It also helps to ensure that non-dementia health issues are not overlooked[13].

Interservice collaboration: transition from community support to care home placement

Planning for the future must take place at an early stage so the person with a learning disability is able to contribute and to share their choices, goals and wishes. This is already part of planning ahead for some families and support services and can help with transition to a care home should it be made at a later stage.

Families, and friends, will need support to undertake advance planning before the person needs care and for many this will be difficult. Transitions may take place at a time of crisis which is why forward planning is important to ensure information is in place. Information must be provided in accessible formats. Person centred communication tools will also enable the person to make informed choices and decisions.

To facilitate a supportive transition from community support to care home admission, it is recommended a clear pathway is agreed. The pathway will incorporate transition planning meetings involving agencies currently involved in the individual’s care and support, their family and/or carer and designated care home provider. This will be informed by local support package review arrangements where a need for a care home move is discussed. If a care home provider who can meet the person’s needs has been identified, they may be invited to the transition meeting(s) before the move. Care home providers can also be invited to hospital discharge planning meetings, if they have expressed an interest in supporting the person. At the transition meeting, any support required by the provider will be identified and a care home support plan will be agreed.

People living with a learning disability and dementia may be using services in the community including day services and social support. This must continue to maintain their physical, psychological and emotional health. This must be agreed before the person moves. Traditionally many of these services are stopped but they are central to the person’s wellbeing and must be part of the commissioning of the service from the beginning.

Interservice collaboration: following admission to care home

The multiagency team will continue to be involved following admission to care home. This may be the multidisciplinary community learning disability team (CLDT) or other teams who support people with a learning disability in health and social care partnerships. It should also include the community support provider the individual received before the care home placement. The purpose of this support is to equip care home staff with the confidence, knowledge and skills to meet the care and support needs of the individual. It will also ensure a supportive transition from community support to care home placement for the individual with a learning disability and advancing dementia.

Support will include continued multidisciplinary input from health and social care partnerships who will continue to:

- attend case review meetings for the individual
- address training and support needs, and provide information and advice, and
- visit the individual to support their transition.

Resources to support multidisciplinary collaboration are listed below.

Resources

A Picture of Health
Making Health Information Easier
www.apictureofhealth.southwest.nhs.uk

Care Inspectorate
Personal planning guides for providers; Adults
hub.careinspectorate.com/how-we-support-improvement/care-inspectorate-programmes-and-publications/personal-planning-guides-for-providers/

Easy Health
www.easyhealth.org.uk

Innovation Agency
Anticipatory Care Calendar
www.innovationagencynwc.nhs.uk/our-work/health-and-social-care/patient-safety/acc

Scottish Government
Health and Social Care Standards: my support, my life
www.gov.scot/publications/health-social-care-standards-support-life/documents/

Wales Mental Health in Primary Care
Disability Distress Assessment tool
www.wamhinpc.org.uk/sites/default/files/Dis%20DAT_Tool.pdf

Environment

My care home will ensure my environment has dementia-friendly design.

The settings in which we live and work have a profound influence on our physical and psychological wellbeing. Ageing, dementia and other health conditions can impact our ability to independently navigate new environments.

A decline in sensory, mobility or cognitive abilities can influence independence, affect functioning and impact on quality of life.

People living with dementia may experience challenges navigating their environment independently for a number of reasons:

- getting lost as a result of memory impairment
- not recognising the purpose of the environment and objects within it (especially if modern)
- misperceiving objects/things
- having reduced colour and contrast sensitivity
- having increased sensitivity to noise, and
- having loss of depth perception.

The changes experienced by people living with a learning disability and dementia can make the environment unfamiliar, unpredictable and frightening. This can lead to people experiencing stress and distress.

A dementia-friendly environment helps people living with a learning disability and dementia reach their full potential and maintain their independence. Dementia-friendly design can help to:

- support decision making
- reduce stress and distress
- encourage independence and social interaction
- promote safety, and
- enable meaningful and purposeful engagement.

This leads to improved outcomes and experiences for people their families and staff.

There are five basic criteria for creating the optimal environment to support the wellbeing of people with a learning disability and dementia listed in the table below. All should be considered in the context of each person living with a learning disability and advancing dementia.

Environment overview

Familiar

Because of my short-term memory loss, my reality may be at some point in the past. For me to feel safe and at home, the environment should be familiar to me. Furniture, fixtures and fittings should be recognisable in my reality.

- The environment should be recognisable as a home. This means the environment I live in should be small and homely.
- Furniture should be age appropriate. This may be the type of furniture I remember from my parents' home or my own home when I was younger. This may make the environment appear dated or old-fashioned but modern furniture may not be familiar to me.
- I may not recognise mixer taps in my kitchen or bathrooms. Separate hot and cold taps may be more recognisable. I may no longer recognise a shower and may even be frightened by it. It may be better to offer me a bath.
- Curtains should be used rather than blinds and light fittings and lamps should be age appropriate.
- Clocks should be recognisable and not digital and appliances I may wish to use such as kettles, radios or record players should be easy to use and familiar. Clocks can be useful to help orientate me to time.

If I lived in my previous home for a long time, it may be helpful to recreate my bedroom in the home as much as possible. This may help me feel safe and secure and help me settle into my new home.

Calm

As my dementia progresses, I may become anxious, stressed and distressed very easily. The environment should be quiet, calm and relaxed to reduce the likelihood and impact of this.

Environment overview

- Noise levels should be reduced as much as possible. The competing noise from television, radio and other people talking could be overwhelming for me and may lead to me experiencing stress and distress.

Too much activity and too many people in my environment may be distressing for me. This should be considered when planning group activities. Small and quiet spaces that are still communal should be available for me.

Predictable

The changes I experience because of dementia lead to increasing difficulties recognising and engaging effectively with my environment. There are many ways you can help me to find my way around my home and maintain my skills and independence.

- I may find it increasingly difficult to find my way around my home. Signage will help me find where I want to go such as my bedroom, toilets and the lounge. Signs must be recognisable to me. The colour and contrast of signs should be considered to make them easy to see. The height of signs should also be considered. For instance, for people who use wheelchairs or are small in stature.

- Colour and contrast are important to help me find where I want to go. Bathroom and toilet doors should be painted the same colour which is different from the rest of the doors. My bedroom door should be recognisable to me. Things that may help could be photographs of me when I was younger, pictures of things or people I like or memory boxes outside my door. It is important that these are at the right height, which is in my eyeline.

- Décor in toilets should be considered to ensure I can see the toilet, for example, a picture of a toilet on the door. This will help me to find the toilet and maintain my continence, dignity and self esteem. Toilet seats should be in contrasting colours as this will make it easier for me to see.

- I may forget what is in cupboards and drawers in my home. To enable me to do as much as I can on my own, putting pictures or photographs of what is in the cupboards or drawers may help. These must be big enough for me to see what they are. Glass or perspex doors would also be helpful.

- The height and depth of sofas, armchairs and dining chairs should be considered to ensure my feet touch the floor and I can get up independently.

Environment overview

The furniture should not be rearranged as this may cause me to become confused and distressed.

Make sense

As my dementia progresses my reality is changing. Some things in my environment no longer make sense. I have increasing difficulty seeing in 3D. This can alarm me and lead to me becoming fearful and distressed. These are some of the areas that may cause problems for me:

- Stepping across thresholds from one room to another may be difficult for me if the carpets or floor coverings are different colours. This may look like a step, and you may see me attempting to climb the step. The threshold bar is often a different colour which is an additional problem.
- Patterns in carpets may appear to me as holes. You may see me trying to step over the holes. I may appear fearful and become distressed.
- Shiny and glittery floor coverings, often used in kitchens and bathrooms may look like a pool of water to me. I may try to avoid entering a room or become distressed.
- In my reality I may be much younger. I may not recognise myself in the mirror. This could cause me stress if I think a stranger is in my home and I may become distressed. Mirrors should be removed in this case, even if temporarily or at certain times of the day.
- In order for my environment to make sense it is essential my ability to navigate my environment is maximised by ensuring my ability to see and hear is optimal. I should have access to hearing and eye checks as appropriate and please make sure I am wearing my own glasses and/or hearing aids–hearing loss and visual impairment is more common in people with a learning disability, especially people with Down’s syndrome.

Good lighting is essential to support me to navigate and understand my environment. Eyesight deteriorates with age and for people with dementia this is further compounded by the ability of the brain to process visual signals.

Suitably stimulating

Environment overview

Environments that are too noisy and busy can be distressing for me. However, the environment must provide enough stimulation to ensure I do not become bored and under stimulated.

- I may enjoy sitting by a window where I can watch people go by. Windows should be low enough to enable me to see out. Blinds and curtains should not restrict my view.
- I may not be able to recognise or respond appropriately if I am too hot or cold. I need staff to check with me regularly and adjust heating to ensure I am comfortable. If I am too hot, I may fall asleep. This will affect my ability to sleep at night and could increase my levels of confusion and increase the risk of social isolation.
- If I do choose to sleep during the day then there are suitable activities and companionship if I am awake at night.
- I should be supported to spend my time in ways that are meaningful and purposeful for me. Staff should ensure activites are matched to my current level of ability and interests. This will improve my experiences and outcomes.
- I need staff to ensure that the levels of light in my home enable me to see what I am doing and where I am going. I also need to be protected from glare.
- I should have access to safe, accessible outdoor space. This is important to maintain my health and wellbeing. I should be able to access the space independently while I can.

Resources

Care Inspectorate
Care Homes for Adults – The Design Guide
www.careinspectorate.com/images/documents/6583/Care%20Homes%20for%20Adults%20%E2%80%93%20The%20Design%20Guide.pdf

Dementia Action Alliance
The Stirling standards for dementia-friendly design
www.dementiaaction.org.uk/assets/0000/7618/dsdcthe_stirling_standards_for_dementia_120430_1.pdf

Resources

Quality Compliance Systems
Digital Pool Activity Level (PAL) Instrument
www.qcs.co.uk/digital-pool-activity-level-pal-instrument/

The King's Fund
Improving the patient experience
Developing Supportive Design for People with Dementia
The King's Fund's Enhancing the Healing Environment Programme 2009-2012
www.kingsfund.org.uk/sites/default/files/field/field_publication_file/developing-supportive-design-for-people-with-dementia-kingsfund-jan13_0.pdf

University of Stirling
Good practice in the design of homes and living spaces for people with dementia and sight loss
shop.dementia.stir.ac.uk/products/good-practice-in-the-design-of-homes-and-living-spaces-for-people-with-dementia-and-sight-loss

University of Worcester
Dementia-Friendly Design Tools
ext-webapp-01.worc.ac.uk/kings_fund

Physical health needs

My care home will ensure my physical health needs are met.

Advancing dementia is not the same as end of life care and should not be responded to or supported in the same way. Similarly, palliative care is not the same as end of life care, as a palliative approach may start much earlier in the course of dementia. Although people with a learning disability are often at, or near to, advancing dementia when a move is made to a care home, this does not mean that it is too late to begin a palliative approach, however it should not be assumed that the person is at the end of their life.

Physical health needs definitions

"Advanced dementia is associated with the later stages of illness when the complexity and severity of dementia-related changes in the brain lead to recognisable symptoms associated with dependency and an escalation of health care needs and risks. Addressing advanced dementia-related health needs requires expert health care, nursing and palliative care assessments together with insights provided by family carers and others, particularly when the person has difficulty communicating their own needs and emotions[14]."

Alzheimer Scotland (2019)[14]

"Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual[15]."

World Health Organisation (2020)[15]

"Patients are 'approaching the end of life' when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days)[16]."

Leadership Alliance for the Care of Dying People (2014)[16]

It can be difficult to recognise when a palliative care or end of life care approach is required, especially given the gradual trajectory of advancing dementia. People living with a learning disability are more likely to have unidentified health needs which can also make recognising the end of life phase difficult. They are also less likely to be referred to specialist palliative care[17]. There are tools which can support this and support the identification of unmet or changing needs. It is important if someone has been identified as requiring a palliative or end of life approach that this is communicated to the person's family and friends as well as staff.

As a person's dementia advances, their physical healthcare needs increase (people with a learning disability may also have multiple comorbidities that will require additional support and treatment, such as arthritis). This may lead to a requirement for equipment such as a wheelchair, specialist seating, moving and handling equipment and a specialist bed. Appropriate assessment tools, such as the St Oswald's Hospice Distress and Discomfort Assessment Tool (DisDat), should be used to ensure people's pain is effectively identified and managed**.**

It is essential a care co-ordinated approach is established to ensure that a person living with a learning disability and advancing dementia has appropriate access to all those professions and services required to meet the range of their needs. For example, if the person has any difficulties with eating, drinking and swallowing, this may involve communication with all of those involved in their care in order to balance their comfort, wellbeing and enjoyment of eating and drinking against their safety. Restricting their diet in order to reduce the risk of aspiration might compromise their nutrition and hydration as well as their psychological wellbeing, so these decisions must be managed with full consultation and care. These issues should be discussed and agreed as part of the advanced care planning process.

Relevant professionals may include:

- GP
- Social Worker
- Social Care Worker and/or Key Worker
- CLDT
- community nursing
- allied health professionals
- pharmacy
- specialist palliative care, and
- speech and language therapist.

Physical health needs

Ensure my physical needs are assessed and appropriate equipment provided to ensure my comfort and safety.

Seek the contribution of others if required eg GP, occupational therapy, physiotherapy, speech and language therapy, dietetics, moving and handling co-ordinators, specialist palliative care

Resources

Bild
Growing Older with Learning Disabilities
www.bild.org.uk/growing-older-with-learning-disabilities-gold/

Care Inspectorate
Personal planning guides for providers; Adults
hub.careinspectorate.com/how-we-support-improvement/care-inspectorate-programmes-and-publications/personal-planning-guides-for-providers/

Care Inspectorate, Scottish Care and Royal College of Speech and Language Therapists
Supporting people with eating, drinking and swallowing difficulties (Dysphagia) Guidance
www.rcslt.org/wp-content/uploads/media/supporting-people-with-eating-drinking-and-swallowing-difficulties.pdf

Daughters of Charity Service (McCarron, M. and Reilly, E)
Supporting persons with intellectual disability and dementia: quality dementia care standards.
A guide to practice
www.lenus.ie/bitstream/handle/10147/145073/Dementia%20Publication%202011.pdf?sequence=1&isAllowed=y

Healthcare Improvement Scotland
Supporting people nearing the end of their lives to live and die well in their community
ihub.scot/improvement-programmes/community-care/people-nearing-the-end-of-their-lives/

Resources

Learning disability and dementia
Self-guided study
www.learningdisabilityanddementia.org/self-guided-study.html

NHS Education for Scotland and Scottish Social Services Council
Palliative and End of Life Care; A framework to support the learning and development needs of the health and social service workforce in Scotland
learn.nes.nhs.scot/2452/palliative-and-end-of-life-care-enriching-and-improving-experience/palliative-and-end-of-life-care-enriching-and-improving-experience

NHS England
Delivering high quality end of life care for people who have a learning disability
www.england.nhs.uk/publication/delivering-high-quality-end-of-life-care-for-people-who-have-a-learning-disability/

NHS National End of Life Care Programme
The route to success in end of life care – achieving quality for people with learning disabilities
www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/11/End-of-Life-Care-Route-to-Success-learning-disabilities.pdf

Nottinghamshire Healthcare NHS Foundation Trust and Sherwood Forest Hospitals NHS Foundation Trust
Improving End of Life Care for People with Intellectual and Developmental Disabilities Resource Pack
www.bild.org.uk/wp-content/uploads/2020/01/Improving-End-of-Life-Care-for-LD-Jan-2019-FINAL-1.pdf

Palliative Care for People with Learning Disabilities Network
www.pcpld.org

Palliative Care for People with Learning Disabilities Network and NHS England
Delivering high quality end of life care for people who have a learning disability
Resources and tips for commissioners, service providers and health and social care staff
www.england.nhs.uk/wp-content/uploads/2017/08/delivering-end-of-life-care-for-people-with-learning-disability.pdf

Meaningful and purposeful engagement

My care home will enable my meaningful activity needs to be met.

People should be supported to spend their time in ways that are meaningful and purposeful for them. This will support people to have joy and satisfaction in their lives as well as to maintain their skills, abilities and independence and improve their experiences and outcomes.

Meaningful activity can also be linked to hobbies and interests. It is also about making everyday interactions meaningful. The Making Every Moment Count resource highlights how making the most of every moment can make a real difference to a person's quality of life in simple but very meaningful ways[18].

Meaningful and purposeful engagement needs overview

In order to maintain my physical, emotional and psychological health and wellbeing, I must be supported to spend my time in ways that are meaningful and purposeful for me.

My person centred plan will tell staff how I enjoy spending my time now and in the past. This may include information about jobs I did or responsibilities I had in my group home such as drying the dishes or setting the table.

My life story book will help staff get to know me and what and who is important to me. This will help staff talk with me about happy times in my life. My life story should keep pace with the changes I experience as a result of living with dementia. In time, it may be that longer term memories are more prevalent. It should be viewed by anyone I want to share it with. Life story work can be prepared in a range of formats and does not have to be done with a professional.

My care home should work closely with members of my family, friends and previous staff. People who know me and my life history will be able to provide valuable information about my likes, choices, what makes me happy and how I like things done.

I may be more focused on just being with people, watching television or listening to music than taking part in organised activities.

Staff understand that I need support to initiate interactions with them and other residents in the home. This will help my physical, emotional and psychological wellbeing.

Meaningful and purposeful engagement needs overview

I may have had a package of care and support which included social and leisure opportunities. I should be enabled to continue enjoying time in my local community. I may be supported with this by staff from another organisation.

My package of care may have included one-to-one time with staff. I should continue to be supported this way as this will support my physical, emotional and psychological wellbeing.

I should be supported to maintain my skills, abilities and independence. It is important that I am enabled to continue the usual routines that are important to me such as doing my laundry, making snacks and cleaning my bedroom. This will help me maintain my sense of identity and self esteem.

I must be supported to exercise my human rights. I should be enabled to take positive risks so that I can continue to do things that I enjoy and are important to me. My care home must balance what is important for me with what is important to me.

Regular assessments should be carried out. Assessments must be based upon what I can do rather than what I cannot do. This will ensure activities and pastimes I engage in remain failure free.

I will be supported to maintain relationships with the people who are important to me. Family members and friends will tell staff how we enjoy spending time together.

The people I live with may not have met someone with a learning disability before. They could have stereotypical ideas about me that could lead to me being isolated or rejected. Staff will support them to get to know me as a person and help us to build relationships.

Staff can communicate effectively with me using any communication aids that are appropriate for me. Information, including menus and signage is provided in formats that are accessible for me. People will know what can distress me and how to support me in times of stress and distress. Including what helps to reassure me and provide comfort to me. Staff will be aware what not to do as this could add to my distress. This will enable me to make my own choices and decisions.

Below are resources which support meaningful and purposeful engagement.

Resources

Care Inspectorate
Care...about physical activity
www.careinspectorate.com/index.php/news/9-professional/2615-care-about-physical-activity

Care Inspectorate
Personal planning guides for providers; Adults
hub.careinspectorate.com/how-we-support-improvement/care-inspectorate-programmes-and-publications/personal-planning-guides-for-providers/

Care Inspectorate
Make every moment count
www.careinspectorate.com/index.php/news/9-professional/2736-make-every-moment-count

Care Inspectorate, Scottish Care and Royal College of Speech and Language Therapists
Supporting people with eating, drinking and swallowing difficulties (Dysphagia) Guidance
www.rcslt.org/wp-content/uploads/media/supporting-people-with-eating-drinking-and-swallowing-difficulties.pdf

Royal College of Speech and Language Therapists
Five good communication standards
www.rcslt.org/wp-content/uploads/media/Project/RCSLT/good-comm-standards.pdf

Down’s Syndrome Scotland
A Guide to Life Story Work
www.dsscotland.org.uk/wp-content/uploads/2020/01/Life-Story-Booklet-Full-Booklet.pdf

Namaste Care
namastecare.com/welcome-to-namaste-care

NAPA
FREE Resources
napa-activities.co.uk/services/resources/free-resources

Resources

Playlist for life
www.playlistforlife.org.uk

Quality Compliance Systems
The Pool Activity Level Instrument
www.qcs.co.uk/digital-pool-activity-level-pal-instrument/

Sanderson H and Bailey G
Beyond life histories
9 practical ways to deliver personalisation with people with dementia
personalisationanddementia.files.wordpress.com/2013/12/beyondlifehistories.pdf

South Lanarkshire Council
Meaningful activities and activities of daily living for older people
www.southlanarkshire.gov.uk/info/200227/care_for_the_elderly/903/meaningful_activities_and_activities_of_daily_living_for_older_people

St Christopher's (Stacpoole M, Thompsell A, Hockley J)
Toolkit for implementing the Namaste Care programme for people with advanced dementia living in care homes
stchristophers.org.uk/wp-content/uploads/2016/03/Namaste-Care-Programme-Toolkit-06.04.2016.pdf

The Learning Exchange
Talking Points: personal outcomes approach - practical guide
lx.iriss.org.uk/content/talking-points-personal-outcomes-approach-practical-guide

Commissioning, resources and registration

My care home will have the appropriate registration and resources to meet my needs.

One of the main barriers to a person with a learning disability and advancing dementia moving into a care home is a belief that the registration process may be difficult. However, this is a straightforward process.

We would advise the care home to contact their case holding inspector to discuss the proposed admission. Care homes for older people will be registered to provide care and support for older people, who will generally be over 65 years of age. The person with a learning disability may be under 65, particularly if they have Down's syndrome. The other people living in the care home are unlikely to have learning disabilities so their needs may be different. The inspector will ask the care home how they can meet the person's needs along with the needs of the other people living in the care home and ensure they experience good outcomes before agreeing to the admission. People who have supported the person with a learning disability, including family and informal supports, should be included in assessing if the care home will meet their needs and support them in the ways they are comfortable with. An independent advocate can also provide support if needed.

Because people's support needs are complex and there may have been an extensive package of care in the community before moving to a care home, additional support hours may be required above the National Care Home contracted placement rates. The National Care Home Contract currently allows for a variation to the placement costs for additional costs to meet the individual's extra support costs. Clearly, this must be agreed beforehand and a local commissioner must be involved in that process. As well as extra staff, there may be bespoke training and/or bespoke activities that would incur extra costs/extra staff hours. This should be agreed beforehand and written into any additional costs contract so that all parties are aware of the overall cost of the placement. Having this support in place can make the placement successful for the individual and should form part of the contact and commissioning process.

For example, where a support provider was a Department for Work and Pensions appointee for benefits, they may continue to be paid for a few hours per week to manage the person's money. Additional support hours could be funded to allow the individual to go out to attend social clubs and activities, and those hours could be provided either by care home staff or a learning disability-specific support provider. Additional hours may be required for a short period of time, as part of their transition into the care home, or may continue longer term. Specialist staff from the learning disability teams such as occupational therapist or clinical psychologist may also continue to visit the individual when required, to provide advice, training and support.

Summary

In summary, this guidance sets out supports and resources to consider when supporting a person with a learning disability and advancing dementia in moving to a care home, if this is appropriate for them to do so.

For further information, in addition to the resources listed within the document, you may find the following websites and resources helpful.

Resources

Alzheimer Scotland
alzscot.org

Care Inspectorate
careinspectorate.com

Dementia Services Development Trust (University of Stirling)
dementia.stir.ac.uk

ihub (part of Healthcare Improvement Scotland)
ihub.scot

Learning (Intellectual) Disability and Dementia
learningdisabilityanddementia.org

Scottish Commission for People with Learning Disabilities
scld.org.uk

Scottish Learning Disabilities Observatory
www.sldo.ac.uk

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Appendix

Principles

It is expected that the care provided is within the context of the existing principles and standards applicable to people with dementia and people with a learning disability.

Standards and principles

Charter of Rights for People with Dementia and their Carers in Scotland (2011)
www.alzscot.org/sites/default/files/images/0000/2678/Charter_of_Rights.pdf

Standards of Care for Dementia in Scotland: Action to support the change programme, Scotland's National Dementia Strategy (2011)
www.gov.scot/publications/standards-care-dementia-scotland-action-support-change-programme-scotlands-national-dementia-strategy/pages/11/

National dementia strategy: 2017-2020
www.gov.scot/publications/scotlands-national-dementia-strategy-2017-2020

National Dementia and Covid-19 Recovery Plan (2020)
www.gov.scot/publications/dementia-covid-19-national-action-plan-continue-support-recovery-people-dementia-carers

The keys to life (2013-2023)
keystolife.info

Towards Transformation Plan (2021 – 2023)
www.gov.scot/publications/learning-intellectual-disability-autism-towards-transformation

The key guiding principles drawn from all of these sources is summarised below.

Everyone – including people with a learning disability and dementia – should be able to contribute to a fairer Scotland where we tackle inequalities and people are supported to flourish and succeed. They should not experience discrimination on any grounds including age and disability.

People with a learning disability and dementia should be treated with **dignity, respect and understanding**. They should be able to play a full part in their communities and live independent lives free from bullying, fear and harassment.

People with a learning disability and dementia have the **right to access social and legal services** to enhance their autonomy, protection and care.

A Healthy Life: People with a learning disability and dementia enjoy the **highest attainable standard of living, health and family life**. They have the right to access a range of treatment, care and support, including end of life care that respects their wishes. People with a learning disability have the right to a diagnosis of dementia.

Choice and Control: People with a learning disability are treated with dignity and respect, and protected from neglect, exploitation and abuse. They have the right to be provided with accessible information and the support they require in order to enable them to exercise their right to participate in decisions that affect them.

Independence: People with a learning disability are able to live independently in the community with equal access to all aspects of society, including the right to an adequate standard of living.

Active Citizenship: People with a learning disability and dementia are able to participate in all aspects of community and society. They, and their carers, have the right to access opportunities for community education and lifelong learning.

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