

# Community Care and Dementia Learning System event in partnership with Alzheimer Scotland, Care Inspectorate and the University of Stirling

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

Wednesday 8 March 2023  
14:00 – 15:30

Enabling health and  
social care improvement



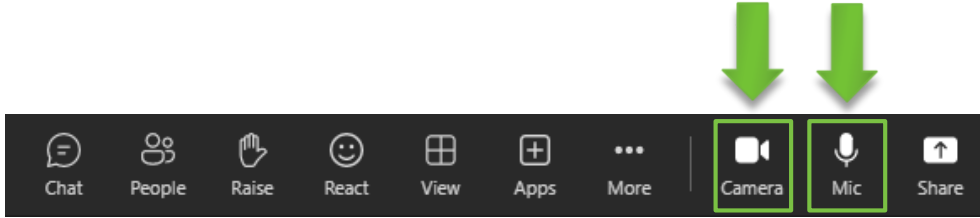
# Welcome

Lynn Flannigan  
Senior Improvement Advisor  
Healthcare Improvement Scotland

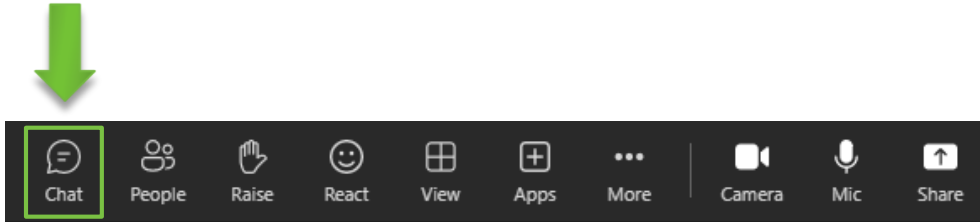
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# MS Teams housekeeping



Your microphone should be muted and video turned off. We have done this to avoid distractions and help minimise the likelihood of slowing down the technology.



Please use the **chat box** to submit questions to our presenters. There will be time after the presentations to answer as many as possible.

**Please note:** the webinar is being recorded and will be added to our website. By joining today you are giving permission for this.

# Agenda

Time	Item	Lead
14:00	Welcome <ul style="list-style-type: none"><li>Context of the guidance</li></ul>	Lynn Flannigan Senior Improvement Advisor Healthcare Improvement Scotland
14:10	Learning disability and advancing dementia <ul style="list-style-type: none"><li>Demographic and definitions</li><li>Why people may need to change accommodation</li></ul>	Jill Carson Consultant Public Policy Alzheimer Scotland
14:25	Challenges people with a learning disability and dementia may face moving to a care home	Sharon Mitchell-Ward Inspector Care Inspectorate
14:40	What is in the new guidance?	Karen Watchman Professor in Ageing, Frailty and Dementia University of Stirling
15:00	Supporting positive outcomes	Sharon Mitchell-Ward
15:15	Audience Q&A	All
15:25	Next steps and evaluation	Lynn Flannigan
15:30	Close	

# Background to the work



Change Package for a  
Dementia Care Co-ordination Improvement  
Programme (post-diagnostic support and care  
co-ordination)

October 2022



# Understanding Learning Disability and Dementia

Jill Carson  
Consultant Public Policy  
Alzheimer Scotland

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# Learning Disability

A learning disability is a significant reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functions), which started before adulthood.

# Dementia

Dementia is not a natural part of the ageing process, but is caused by illnesses that affect the brain.

Dementia is an umbrella term for over 100 different types of diseases and symptoms, and it's possible to have more than one type. What all these diseases have in common is that they damage brain cells, so that the brain cannot work as well as it should.

Dementia can affect every area of human thinking, feeling and behaviour, but each person with dementia is different - how the illness affects someone depends on which area of their brain is damaged.



# Symptoms of Dementia

Memory loss is one of the most common symptoms of dementia, and when someone has dementia they may become very forgetful. For example, they may forget the names of family members or whether they have eaten lunch or not. They may repeat questions without realising.

People with dementia may lose track of the time and day. They may forget where they are or be confused. Their ability to think and work things out can be affected. They may make decisions that seem strange to us. Handling money may become difficult and they may find it difficult to solve problems.

Dementia can also change the person's personality and the way they behave. We are all unique individuals and that's what makes the experience of dementia so diverse.

Over several years, most functions of the brain will gradually be affected, and most people will need help with simple activities such as dressing, eating or going to the toilet.

# Advanced Dementia

“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. Advanced dementia involves living, sometimes for years, with advanced illness and the advanced dementia continuum includes the terminal stages of death and dying. The experience of advanced dementia is unique to the individual and dependent on the aetiology of the underlying illness, comorbidities and other factors relating to health, personality, biography and socio-economics.”

# Delivering Fair Dementia Care For People With Advanced Dementia

The Fair Dementia Care Commission

# Learning Disability and Advancing Dementia

- Advancing dementia reflects continuum and individual approach
- 30% of people with Down's syndrome in their 50s will have Alzheimer's dementia
- This rises to 50% for age 60-70
- Around 13% of people with a learning disability aged 60-65 will develop dementia - compared to 1% in the general population
- Increasing life expectancy means this is a relatively new phenomenon
- Can mean that commissioning is not familiar with the presenting issues
- Planning for the future - increasing population means there will be more people experiencing advancing dementia....
- ....but person centred planning should be the norm

# Considerations for a move to a care home

- Current accommodation cannot provide for the level of support required (eg waking night staff)
- Current accommodation may not be adaptable for the level of physical care required
- Healthcare needs require more significant support eg on-site nursing staff
- When the dementia becomes the source of the primary presenting issues, the person may benefit from an environment specifically designed to support those issues

# Meeting Changing Needs

People with a learning disability are often supported, and supported well, by families and learning disability services

Connecting with other relevant services: dementia, post diagnostic support, palliative care

Multidisciplinary and multi-agency approach to identifying when needs are increasing and no longer best met within current supports and services

Person centred planning - rights and preferences

The needs of significant others in the person's life - family, friends, staff

# Challenges people with a learning disability and dementia may face moving to a care home

Sharon Mitchell-Ward  
Inspector  
Care Inspectorate

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# My New Home

Challenges people with a learning disability and dementia  
may face moving to a care home



# Impact of change

- Crisis moves- Impact on the person
  - Where did I live? What's different?
  - Size of the home
  - Amount of people living in the home
  - Noise levels
  - Layout – finding my way
  - Life experience – institutional living? – staff wearing uniforms
  - Outcomes
  - Where am I?, I don't feel safe. I may experience stress and distress
- ***“The premises have been adapted, equipped, and furnished to meet my needs and wishes (HSCS 5.16)***
  - ***“If I live in a care home the premises are designed and organized so I can experience small group living, including access to a kitchen, where possible” (HSCS 5.7)***

# My care and support

- Staff experience, training and knowledge - person specific and ongoing
- Leadership and support
- Provider/ staff confidence and concerns
- Transferring learning into practice
- What is a learning disability?
- How does this impact on me?
- What's different when the person living with dementia lives with a learning disability?
- Outcomes:
- Staff don't have the skills or abilities to care for and support me. Staff may not recognize when my needs change
- ***“I have confidence in people because they are trained, competent, and skilled, are able to reflect on their practice and follow their professional and organizational codes” (HSCS 3.14)***
- ***“I am protected from harm because people are alert and respond to signs of significant deterioration in my health and well being, that I may be unhappy or may be at risk of harm”(HSCS 3.21)***

## My social and emotional life

- Loss of important relationships, routines and activities
- Other people living in the home may be significantly older
- Communal activities and entertainment
- Relationships with other people living in the home
- Outcomes:

I miss my friends and family. I feel lost and sad. I'm not stimulated and bored

My physical, emotional and psychological health may be at risk

- ***“ I am encouraged and supported to make and keep friendships, including with people my own age” (2.19)***
- ***“I can maintain and develop my interests, activities, and what matters to me in the way that I like” (HSCS 2.22)***

# Feeling valued and safe

- I may not use verbal forms of communication
- I may use alternative forms of communication including Makaton or visual formats
- If people can't communicate with me I may be socially isolated
- I may be unable to tell you when I am in pain or distress
- Staff may not understand or be able to meet my needs
- Outcomes:
- I feel alone, I don't know who you are or where I am. I don't feel safe. I may experience stress and distress
- ***“ I am supported to communicate in a way that is right for me, at my own pace, by people who are sensitive to me and my needs” (HSCS 2.8)***
- ***“ I receive and understand information in a format or language that is right for me” (HSCS 2.9)***

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



**Health and Social Care Standards**  
**My support, my life**

# What is in the new guidance?

Professor Karen Watchman  
Professor in Ageing, Frailty and Dementia  
University of Stirling

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social care improvement





# My New Home

*What is in the new guidance?*

Professor Karen Watchman, University of Stirling  
[Karen.Watchman@stir.ac.uk](mailto:Karen.Watchman@stir.ac.uk)

# Key themes

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- Ensuring a person-centred approach and choice
- Knowledge, skills and training
- Specialists support and multiagency collaboration
- Environment
- Physical health needs
- Meaningful and purposeful engagement

*“Where possible, I should be able to stay in my own home if that’s 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. Ask me.”*



# Ensuring a person-centred approach

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- A strengths based approach to decision making and care planning
- Positive engagement
- A human rights based approach
- Family life
- Anticipatory care planning
- Personal outcomes approach
- Effective communication

*“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”*

# Knowledge, skills and training

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- The Promoting Excellence Framework
- Learning Needs Analysis
- Specialists support and multi-agency collaboration before, during and after transition
- What did people with intellectual disability say?

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

# Physical health needs and the environment

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- Dementia friendly design – familiar, calm, predictable, make sense, suitably stimulating
- Aids, equipment and adaptations
- Multi agency/multi disciplinary approach
- Advanced care planning
- Meaningful, individualised and purposeful

*“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”*



*“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”*

# Supporting positive outcomes

Sharon Mitchell-Ward  
Inspector  
Care Inspectorate

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# My New Home

Supporting positive outcomes

# Positive transitions

- Human rights based approach
- Anticipatory Care Planning – making choices and decisions about my future care and support
- Transition planning – I'm involved in making the plan. It's at my pace, building relationships
- Multi-disciplinary approach – everyone agrees the move is right for me
- Funding- I am enabled to carry on doing the things that are most important to me
- Outcomes:
- The impact of the move is minimized. I am supported to maintain my sense of identity. I know my new staff and where I will be living. I feel safe.
- ***“My views will be sought and my choices respected, including when I have reduced capacity to make my own decisions” (HSCS 2.11)***
- ***“I am supported to discuss significant changes in my life, including death and dying, and this is handled sensitively” (HSCS 1.7)***

# My care planning and support

- I may already have a care plan in place- I may already receive support.
- I can bring my care plan with me
- Accessible formats- my care plan, and all other information, is provided in formats that suit me
- Involve me, my family and other people important to me
- Person centred care and support – what’s important to me as well as what’s important for me
- Life story work – know who I am, what I’ve achieved, what matters to me, what I still want to achieve
- Outcomes:
  - I’m supported to keep being me. I feel safe and secure.
- ***“My personal plan (sometimes referred to as a care plan) is right for me because it sets out how my needs will be met, as well as my wishes and choices” (HSCS 1.15)***
- ***“I am confident that the right people are fully informed about my past, including my health and care experience and any impact this has on me” (HSCS 3.4)***



# Staying well

- Physical, emotional and psychological health and wellbeing – spending ways that are meaningful and purposeful for me
- Maintaining skills, abilities and independence – important routines and habits
- Taking positive, life-enhancing risks -
- Enabling environments:
- Signage – height, size, format
- Lighting – ageing eye, shadow and shade
- My bedroom – can I see the toilet from my bed?
- Outcomes:
- I'm suitably stimulated and engaging with people. I'm doing things I know and enjoy. I am maintaining my continence. I'm still me. I feel safe and secure
- ***“I make informed choices and decisions about the risks I take in my daily life and am encouraged to take positive risks which enhance my quality of life” (HSCS 2.24)***
- ***“I take part in daily routines such as setting up activities and mealtimes, if this is what I want” (HSCS 2.21)***

# Meeting my changing needs

- My needs are assessed on a regular basis
- Multi-disciplinary team - also consider any changes to my social and emotional needs
- Learning disability team input
- Eating and drinking
- Communication
- Assessing and managing pain
- Palliative and end of life care
- Outcomes:
- I continue to enjoy the food and drinks I like safely, I am supported to stay as well as I can for as long as I can, staff ensure any pain I experience is addressed
- ***“ I am fully involved in assessing my emotional, psychological, social, and physical needs at an early stage, regularly and when my needs change” (HSCS 1.12)***
- ***“My future care and support needs are anticipated as part of my assessment” (HSCS 1.14)***



# The keys to life

## Strategic Outcomes - *The keys to life*

### **A Healthy Life:**

People with learning disabilities enjoy the highest attainable standard of living, health and family life.

### **Choice and Control:**

People with learning disabilities are treated with dignity and respect, and protected from neglect, exploitation and abuse.

### **Independence:**

People with learning disabilities are able to live independently in the community with equal access to all aspects of society.

### **Active Citizenship:**

People with learning disabilities are able to participate in all aspects of community and society.

# Audience Q&A



# Next steps and evaluation



<https://ihub.scot/improvement-programmes/focus-on-dementia/>



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@focusondementia

