Essex County Council

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Essex Learning Disability Partnership

Embracing Change Learning Disability Aging and Physical Health – a shared approach

by

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Background

LeDeR reports consistently identify:

- Pneumonia as leading cause of death
- Pattern of frailty and deterioration similar to that in older people
- Frailty had not been identified and mainstream services not involved

Actions

- Engagement with people with learning disability on their experience and wishes around aging
- Commissioning priorities for ELDP specialist LD Health
- Link ELDP with ECC's Aging Well project
- ECC lead on co-producing a Toolkit for Aging Well with a Learning Disability

Outcomes

- Frailty in people with learning disability is better understood and managed.
- People know how to access the right help when someone is showing signs of frailty or age related health deterioration.
- People work together to address the needs of people with Learning Disability who are aging.
- People with learning disability have good quality of life as they age

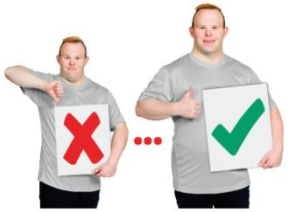
Deliverables to Date

- ✓ Adapted Frailty Assessment Tool appropriate for people with Learning disability/autism
- ✓ Joint training with LA and Specialist Health for social care providers
- ✓ Aging Well Toolkit for Social Care Providers, Social Workers, Adults with LD & their families
- ✓ Dynamic Support register for risk of physical health deterioration which identified frailty and leads into specialist health pathways including health coordination function
- ✓ Local Frailty Forums with specialist health input

Priorities for ELDP

Themes (National and local) - Too many people with a learning disability (LD) are dying earlier than people without LD

- **Annual Health Checks** - A lot of people with LD do not get their annual health check
- **Frailty** – People with LD are experiencing frailty much earlier than people in the rest of the population
- **Health Coordination** – People with LD struggle to access information and service
- **Dynamic Support Register** – Physical health needs are not being identified in people with LD to prevent escalation



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Frailty

LEARNING DISABILITIES

Objective:

Frailty in people with Learning Disability will be understood as part of the dynamic risk register function

Aims:

- ✓ **To understand**
  - the presentation of frailty in people with Learning Disability and its antecedents.
  - issues of access to mainstream frailty services, what adaptations need to be made for people with Learning Disability and the gaps within the service.
- ✓ **To have**
  - consistent preventative measures and messages in place to address the antecedent to frailty across all agencies (mobility and falls, avoidance of LTCs, nutrition etc.)
  - a shared understanding and implementation of care coordination which addresses frailty as part of wider needs.
  - shared programme of training to all stakeholders to ensure there is understanding where there are skill gaps and finding mitigations
- ✓ **To identify** frailty in people with Learning Disability and have clear integrated pathways to prevent health deterioration.

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Definition of LD Frailty

Frailty in people with LD is a presentation of complex health needs, with life limiting reduction in functional ability; such as dysphagia, weight loss, frequent infections, reducing heart and lung function, pain, reducing mobility, falls and behavioural issues etc. People with learning disabilities experience this at much earlier age and if care is not coordinated appropriately, patients are at risk of deterioration in physical and mental well-being.

Significant Risk Tool

Significant Risk Tool for Premature frailty for people with Learning Disabilities.

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Date:	
NHS Number:	
Name:	
Diagnosis/Medical history/Long term conditions:	
Medication:	

Areas of concern	Rating	Score		Comments
Does the person experience confusion? (Does the person experience a neurological condition or acquired brain injury, epilepsy)	No Yes	0 1		Is there a change within the last three months? Is this linked to infection or change in neurological condition?
Mood: (Changes in behaviour, communication, speech, deafness).	No Yes	0 1		Is there a change within the last three months? Is the behaviour linked to infection? Is the behaviour linked to pain? Is there behaviour linked to mental or physical health

				conditions? Are there concerns the person struggles to communicate pain?
Does the person have respiratory difficulties/conditions? (Any known breathing problems?)	No Yes	0 1		Is there a change within the last three months?
Does the person have cardiovascular conditions? (cardiac disease, high cholesterol, high blood pressure)	No Yes	0 1		Is there a change within the last three months?
Does the person have problems? with their nutritional intake? Current BMI (1: BMI 15 -18.5, 25 – 30; 3: BMI under 15 or over 30) Is there a weight change?	No Yes –minor Yes-significant	0 1 2		
Hydration: (Are they able to eat and drink independently or with physical support from another?)	No Yes	1 0		
Does the person have dysphagia concerns?	No Yes- Minor Significant	0 1 2		Is there a care plan in place? Are dysphagia concerns managed? Are there concerns about dehydration, coughing?

				Have there been recent hospital admissions in relation to aspiration?
Toileting Incontinence/constipation/ changes in toileting patterns/UTI	No Yes- Minor Significant	0 1 2		Recurrent UTI? Observations of bloating Expressing discomfort Vomiting- discoloration in vomit? No response to medication i.e lactulose Changes in behavior/unsettled/ abilities? Hospital admissions?
Does the person have difficulties with their posture or mobility	No Yes: Minor Significant	0 1 2		Have there been any changes in mobility/posture in the last three months? Have there been any falls in the last three months? Has function changed within the last three months.

				Has there been a change in the last three months in the nature of the falls (intensity and frequency)
Skin integrity (pressure areas, waterlow score, general appearance, signs of mottled skin	NO Yes- Minor Significant	0 1 2		Any changes in skin appearance? Waterlow Score: Dramatic change in waterlow score Ongoing concerns about skin changes.
Does the person experience pain?	No Yes Managed Unmanaged	0 1 2		What causes the pain? Where is the pain? Has the management of the pain changed in the last three months? Is the pain acute/chronic? Is the pain impacting on behaviour and presentation? Is the pain impacting on abilities to perform daily living skills?

				Is the pain linked to a fall/injury/bone deformity etc.?
Admission to hospital	No Yes	0 1 2		 1 hospital admission within 3 months. 2or more hospital admissions with three months.

Score	Rating	Considerations
0-4	**Mild**	**Annual health check**
5-7	**Moderate**	**MDT on issues identified within the assessment**
8+	**Severe**	**Frailty formulation/clinic sessions Review of care plan Escalation of concerns to GP other clinical professionals involved.**

Risk considerations:
Communication:
Dementia/Suspected Dementia:
Limited Support network: Concerns around disengagement (linked to diagnosis i.e Autism)

Signed:

Title:

Date:

Case Study

Mr X

- 70 year old gentleman.
- Living in supported Living
- History of Korsakoff Psychosis
- History or self neglect and deterioration in physical and mental health
- This gentleman was able to engage in the completion of the tool and was used as a way of helping work on collaborative goal setting to maintain physical health.

Miss Y

- 76 year old lady
- LD, Autism, COPD, Dementia, difficulty with swallow.
- Tool completed with MDT- helped to start care planning and identify specialist assessments that need to be completed.
- Carers part of the tool completion.

Ageing well Toolkits

- Came about following the Service Provider training Sept/Oct 2021
- Evolved into a tool kit to support practice change
- Produced in collaboration with LD specialist health colleagues, to make it a jointly owned document and agreed process
- Versions of the Toolkit
  - Service Providers
  - Reviewers
  - Families and Carers
  - People with Learning Disability with/without Autism

What does the toolkit look like?

https://www.essexproviderhub.org/adults-with-disabilities-hub/ageing-well-with-a-disability-toolkit-for-providers/overview/

Next Steps

- Further integration with mainstream health services
- Extension of shared training and approach with Thurrock and Southend
- Co-production of an accessible version of the Toolkit for adults with learning disability and their families/carers
- Join up with dementia workstreams
- Continued joined up approach towards “Dying Well” and End of Life
- Review of outcomes with Experts by Experience