

## Learning into Action – Report on LeDeR Reviews Involving a Cancer Diagnosis.

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### Introduction

Widespread innovation in NHS Cancer services has achieved a steady increase in cancer survival over the past 40 years but we still have unmet need and unexplained local variation. <sup>i</sup>

One-size-fits-all services have often failed to engage with the people most in need, leading to inequalities in access and outcome. The NHS Long Term Plan makes a commitment to increase the proportion of people diagnosed with cancer at stage 1 or 2 to 75% over the coming decade. Without addressing the widening care-gap we are unlikely to achieve this target.

This report reviews cancer related recommendations from National LeDeR Programme Case Reviews and makes recommendations for Cancer Alliances to reduce inequality in cancer services for all vulnerable groups.

The LeDeR programme focus is on learning disability. However, many of the learning points apply more broadly and the programme has the potential to improve cancer outcomes in the whole population. The reviews included in this report address common themes that are relevant to adults who lack capacity, those with frailty and those with reduced understanding of the implications of unwise decisions and the signs and symptoms of cancer.

The principles of communication and reasonable adjustment of care apply to many people who do not have a learning disability and consideration of the learning points more broadly could help reduce breaches in 62-day performance. Applying the learning from these reviews is essential to achieve the ambitious target of early diagnosis of cancer set out in the NHS long-term plan.

### The LeDeR Programme

The Learning Disabilities Mortality Review (LeDeR) Programme <sup>ii</sup> was set up as a result of one of the key recommendations of the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). CIPOLD reported that people with learning disabilities are three times more likely to die from causes of death amenable to good quality healthcare than people in the general population.

LeDeR aims to make improvements in the quality of health and social care and reduce premature deaths for people with learning disabilities.

The major role of the LeDeR Programme is to support local areas in England to review the deaths of people with learning disabilities ages in order to:

- Identify potentially avoidable contributory factors to the deaths of people with learning disabilities.
- Identify differences in health and social care delivery across England and ways of improving services to prevent early deaths of people with learning disabilities.
- Develop plans of action to make any necessary changes to health and social care services for people with learning disabilities.

## Methods

All completed LeDer review cases were analysed in October 2018 to identify those with a cancer diagnosis listed as a cause of death. The reviews were completed by lay professionals who collected information from family members, care providers and health care professionals before making recommendations of best practice and care that could be improved.

These recommendations are collated into themes that correspond to Cancer pathways and presented with recommendations for Cancer Alliances to put learning into action.

Table 1: Cancers Identified

Colorectal	20
Upper GI	18
Haematology	15
Urology	11
UK primary	10
Lung	8
Breast	8
Gynae	7
CNS	4
Head and neck	2
Skin	1
Neuroendocrine	1
Total	105
Total LeDeR cases reviewed	826

## Key Themes

Lack of knowledge of needs of people with learning disability in Cancer teams. Examples include family engagement, mental capacity, consent, resuscitation decisions. Lack of knowledge of needs of people with Cancer in Learning Disability teams. Examples include lack of awareness of symptoms of cancer and palliative care protocols.

- Cancer diagnosis at an advanced stage, prompting an end of life care pathway.
- Diagnostic overshadowing: a tendency to attribute all other problems to the Learning Disability diagnosis.
- Access to investigations limited by lack of reasonable adjustment to care and assumptions around ability or willingness to tolerate.

## Prevention and Screening

People with learning disability have a reduced understanding of risks associated with behaviours such as smoking, poor diet and lack of exercise and a reduced understanding of the importance of screening. <sup>iii</sup> A number of studies have reported low uptake of health promotion or screening activities among people with learning disabilities. <sup>iv</sup> Several LeDeR reviews reported on the potential impact of lifestyle and poor screening uptake on the development of cancer. A regular theme in the reviews was the importance of GP Annual Health Checks to support informed decision making and reasonable adjustment to health promotion activities. <sup>v,vi</sup> The importance of working with LD care providers in promoting healthy choices was highlighted. There was also regular mention of good practice in health promotion work. In one case a GP visited a residential care provider to provide information about screening for residents and staff to encourage uptake.

This gentleman was a strong-minded individual who would regularly ignore good advice from the range of people who were thinking about his best interests. For example, his refusal to take medication, to attend annual health checks, to attend preventative health measures was a cause of concern.

The Care Home were very supportive and appear to have gone out of their way to ensure Fredrick's needs were met. The carers encouraged Fredrick to have reduced strength cigarettes and to smoke less often. Everyone involved worked together to ensure a co-ordinated approach.

### Recommendations made by reviewers:

Consider commissioning an enhanced annual health check for people with LD who engage in high risk behaviours. For example; those who smoke or meet targeted lung health check criteria. <sup>vii</sup>

Move towards smoke free care environments.

Target LD residential care homes in help to quit programmes.

Development of guidance on assessing the impacts of a refusal to follow advice within a Best Interests/ Mental capacity framework to include adjustment to delivery of advice and bespoke monitoring for those who continue with high risk behaviours.

### Learning into action

Access to health promotion, screening and quality of GP Annual Health checks was a theme of many reviews where a Cancer diagnosis was not made and would be worthy of a separate report.

Lack of screening uptake and unwise lifestyle decision making is not limited to LD population and much of the learning from these reviews will apply to all vulnerable groups.

## Early Diagnosis.

The LeDeR cases reviewed for this report consistently reported cancer diagnosis at an advanced stage. A number of cases reported diagnostic overshadowing where red flag symptoms were attributed to a different non-sinister cause and therefore not acted on. Lack of professional curiosity was reported amongst a variety of health care professionals and care staff. One reviewer felt carers had contributed to a delay in diagnosis by offering the view that symptoms could be behavioural, to which the GP agreed. Some reviews reflected a lack of physical health awareness and assessment skills amongst the LD workforce with a culture of assuming behaviours are psychological or social in origin rather than considering a change in physical health. There was also a lack of awareness amongst care staff of softer signs of cancer such as weight loss and poor appetite.

It was stated in the notes numerous times that a urine sample couldn't be collected due to her incontinence and so symptoms were often treated as a UTI without confirmation. Clinicians need to be more curious and question why a patient is repeatedly treated with an antibiotic such as Trimethoprim.

Carers raised concerns about Fred's cough two years before the oesophageal cancer was found. GP focus was on reflux and respiratory infections (antibiotics were prescribed, which had no effect). Potentially his cancer could have been diagnosed sooner and the possibility exists that earlier treatment could have prevented his death.

Tim was recently diagnosed with metastatic oesophageal Cancer, he lived on his own with family support. Tim informed the staff in hospital of him losing weight. His sister felt that no one had listened to him.

### Recommendations made by reviewers:

Consideration of trigger for patient review, when use of urgent appointments prevents consistency of practitioner.

Consider training for GP Annual health checks in the identification of individuals at risk due to age, family history, health or illness behaviours and anticipatory care planning for early detection of cancer. Screening tools specific to signs and presented symptoms. E.g. Stool chart reviews.

Consider using devices such as toilet urine or stool collection aids. Learning events for care staff on significant signs and symptoms e.g. weight loss, loss of appetite, abdominal distention, constipation, pain, bleeding, difficulty swallowing and of how changed behaviours may be an articulation of a physical health problem which may need urgent investigation and treatment.

Ensure that at Annual Health Check screening attendance is considered, and where someone has not attended try to find a way for them to get the support they need to attend, if appropriate.

### Learning into Action

Develop accessible information on risk factors for cancer, what to look for and what to do if symptoms appear and the importance of early diagnosis of cancer

Work with specialist cancer teams to develop guidance on obtaining urine samples when patients are incontinent and on when further lengths should be taken to obtain a clean sample.

Work with LD specialist teams on guidance on recognising physical health as cause of behavioural change for families, carers and health professionals.

## Access to investigations.

Patients in the cases reviewed consistently had poorer access to investigation than the general population. There was often a long time from initial symptoms to tests being performed or a referral being made. In some cases, care teams made the decision not to refer for tests without a clear best interest decision documented. There were consistent reports of poor uptake of screening programmes with DNA recorded without consideration of whether a reasonable adjustment could support successful testing in future. Several cases reported barriers to investigation once referral had been made such as failed bowel preparations and claustrophobia resulting in a lost appointment and referral to an open scanner. One review noted the impact of a patient moving GPs which almost re-set the timeline for bowel investigations.

Under the Equality Act 2010 <sup>viii</sup>, health services must consider the needs of people with disabilities in the way they organise their buildings, policies and services. These are called 'reasonable adjustments' and reflect that fact that some people have needs that standard services do not adequately meet. This could relate to a wide range of people including those with learning and/or physical disabilities, those with dementia and people living with mental health problems.

As a system we can be sensitive to people's needs, recognising if a person has a communication problem that requires a tailored approach, or a physical problem that makes accessing and negotiating the building difficult, or is particularly anxious about engaging with health professionals and needs a bit more time and reassurance. <sup>ix</sup>

Some reasonable adjustments can be provided as standard part of the service for example clear signposting. Some can be provided as a standard part of an individual's care, for example an interpreter for someone with communication difficulties. Some may be specific to the individual in the context of the proposed service and need to be tailored accordingly.

Primary care services have an important role in considering the needs of people with disabilities and including this information with any referral communication. Secondary care providers can help by providing clear information to GPs of what patients can expect following a referral.

The language used by some professionals to describe potential obstacles linked to medical procedures i.e. that it "will be difficult" or "would not be possible" - with the inference being that these challenges may occur because of a learning disability diagnosis.' 'There was some suggestion that because he had a learning disability he would not comply'

His usual response to care interventions was to swear and try to hit/scratch carers. An earlier intervention to manage this may have resulted in a better outcome in his later years.

'The staff team were passionate about the care they delivered. There was evidence in the notes that they followed up concerns about a resident's health and voiced their concerns when they felt further investigation was required and were able to suggest solutions when it was thought he would be incompliant with clinical interventions.

## Recommendations made by reviewers:

Consider reasonable adjustments to accommodate alternative approach to investigation e.g. support with bowel preparation for colonoscopy.

Avoid assuming a test will not be possible. Support best interest decisions around relevant tests to rule out malignancy, such as considering the least restrictive tests first. Under the Mental Capacity Act this also includes liaison with family members, or if no family or friend outside of services then an Independent Mental Capacity Advocate (IMCA) be appointed

Use accessible information to ensure adults understand the significance of declining tests.

Make best use of care staff who know their residents well by keeping them included and informed.

Consider training for carers in screening programmes and how to explain tests to support informed consent.

Carers to take responsibility for access to tests rather than the adult who lacks capacity.

Support primary care liaison roles to improve communication between GP, care staff and hospital.

Consider 'Did not attend' or 'Not brought to appointment' follow-up systems in primary care.

## Learning into Action

Reasonable adjustments section to be added to 2ww referral forms and investigation requests.  
Better use of annual health checks to inform reasonable adjustments to care in the event of symptoms that could be related to cancer.

Easy read information on risk associated with testing and not testing in presence of red flag cancer symptoms including the contribution of genetic and lifestyle risk factors.

## Cancer Treatment

Reports attributed excellent quality of care to involving the family and allowing them to act as advocates throughout. Holding regular family and professional meetings, keeping the family up to date with patient's condition and any issues in delivering care; Adopting flexible visiting hours to support patients and families for example allowing a patient's mother to stay two nights with patient when patient was approaching end of life.

There were reports of poor understanding of Mental Capacity Act by hospital staff. One report highlighted a lack of clarity around who owned the best interest decision causing a long delay in meetings being convened and decisions being made. On two occasions ward staff would not share information with carers. Professionals need greater understanding of the role of the carer and the benefits of keeping them informed.

Several reports highlighted the importance of good communication between services. e.g. hospital, social worker, GP, Palliative Care Team, District Nursing, Community Learning Disability Nurse and involvement of family. Clear communication of staff roles and responsibilities to patients, carers and staff helping reduce anxiety and delays in care. The use of different systems and information being held in different places made some communication difficult. There were areas for improvement highlighted such as the importance of listening to family members for any concerns they may have regarding changes in behaviour patterns and new symptoms.

James underwent staging in preparation for surgery. This included an MRI scan and laparoscopic examination. It was following this procedure that it is believed the tumour perforated and he died. There was no evidence in his hospital notes that he had a learning Disability diagnosis. There was an attempt to contact his key worker but this did not happen. This was further compromised as he was out of area in hospital. James had no family, there is no evidence that an advocate was consulted to support him in decision making. There was no evidence of reasonable adjustments being made There was no evidence around his capacity status which would have impacted on serious decision making and consent.

Linda's sister reported that she felt she needed to be present in the hospital as doctors or nurses did not know Linda had a learning disability and needed to be reminded constantly

The Community Matron felt that Maureen would be best treated outside of hospital but as no formal discussion she went back and forth to hospital

### Recommendations made by reviewers:

Informing LD liaison nurses when admitted to a general hospital for treatment.

Mental Capacity Assessments to be done more frequently and the paperwork included in the notes. This is not happening routinely.

### Learning into Action

Use of annual health checks and hospital passports to support;

- Best interest decision making.
- Clarity around who can be communicated with without breaking confidentiality.
- Difficult conversations

Training for GPs and hospital staff in MCA, best interest decision making and reasonable adjustments to care.

Information for families and support staff to help them understand the new terminology and procedures.

## Difficult Conversations

People with learning disabilities should be fully informed of conditions and diagnoses, particularly those that are life-limiting, to enable involvement in End of Life care planning. This information should be person-centred, with consideration given to the impact on the patient with appropriate support following. Where appropriate, this should follow consultation with those who know the person well, to ensure the information is given in a measured way and may include the use of easy read information to help someone understand.

Several reports raised concerns about informal decision making to not give information and bad news being given in an unplanned way. Informing a person with learning disabilities of a terminal diagnosis is challenging for all involved and involvement of the Learning Disability Team to support this is advised. One report commented on relatives feeling at a loss with what might be expected, recommending nursing and care team check in regularly with relatives even if they give off a capable air.

### Recommendations made by reviewers:

For older adults with LD 'thinking ahead' tools should be used to consider; writing a will, funeral planning, power of attorney, next of kin etc. This can avoid delays in funerals taking place.

Freda was informed of her diagnosis by an acute liaison nurse, and prior to this had not been made aware. It seems an informal decision had been made not to tell her as it would cause distress. The information is said to have 'devastated' the patient. The patient's family and carers were not involved in this process.

Despite having a care worker present at the outpatient appointment, the care worker was unclear if Rob had really taken on board the end of life discussions and what the prognosis meant for him. The care worker was able to translate the conversation and support Rob so that he could understand what was being explained.

## Best Practice

After reviewing both the life and death of Jane, I come to the conclusion that she was born into an extremely loving family whom cared for her dearly. Until the time Jane required social services input at the age of 65 years her parents and siblings cared for her. Jane then was provided a tailor-made care package that helped her lead a life fulfilled with all the things she liked to do whilst remaining as independent as possible in her family home. Her hospital admissions were all to the same hospital and ward and a fantastic relationship with staff, carers and family was well recognised by all who cared for Jane. A tailor-made care package was formed for 6 years that enhanced Jane's life and care.

I really believe that Christine received a very good level of care during the last year of her life. This was demonstrated by:

- a flexible GP who communicated well with the network offering home visits and seeking advice and support from the network when required;
- good reasonable adjustments made during investigation stage and treatment planning;
- a very good care coordinator (community nurse) who knew Christine well and was able to monitor both Christine's mental and physical health advised newer health professions to the network what was Christine's baseline;
- good end of life care planning;
- Christine was kept at home and she had a great level of support going into her home; district nursing, palliative care nurse, community nurse, psychiatrist, GP;
- a super staff team supporting Christine who were very caring and dedicated to giving Christine the best care;
- A very good palliative care nurse who the staff really valued and found hugely reassuring;
- great communication across the network shown in emails and meetings

There was a sense that despite Christine not having any family members that the network cared about making sure her care was person centred and in her best interest.

From the point of Mr Smith's diagnosis in January 2017 until his death in July 2017 the reviewers found evidence of a strong collaborative partnership between health care professionals and social care professionals from the local learning disability team; community nursing, speech & language therapists, physiotherapy and social worker, hospital clinicians, GP, district nurses and the community matron. The learning disability nurse was the named co-ordinator and she organised for the network to meet regularly with Mr Smith and his carers to review his anticipatory care plan. All Mr Smith's care was delivered in a very person-centred way and he was supported to fulfil his wishes, including a trip to the seaside with his friends to celebrate his 86th birthday.

## Conclusion

Although people with LD represent a relatively small proportion of those diagnosed with cancer, the recommendations of reasonable adjustment to care, professional curiosity and improved communication have the potential to improve early diagnosis and experience for all vulnerable groups.

<sup>i</sup> Cancer and the NHS Long Term Plan

<sup>ii</sup> The LeDeR Programme (2015-2018) is run by the University of Bristol and commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England.

<sup>iii</sup> Improving the health and wellbeing of people with learning disabilities Guidance for social care providers and commissioners (to support implementation of the health charter) Revised September 2015

<sup>iv</sup> [https://www.ndti.org.uk/uploads/files/Screening\\_Services\\_Strategy\\_Toolkit\\_final.pdf](https://www.ndti.org.uk/uploads/files/Screening_Services_Strategy_Toolkit_final.pdf)

<sup>v</sup> <https://files.digital.nhs.uk/BA/4F4C1D/health-care-learning-disabilities-1718-sum.pdf>

<sup>vi</sup> <https://www.hsj.co.uk/quality-and-performance/new-data-reveals-shocking-uptake-of-yearly-health-checks/7024295.article>

<sup>viii</sup> [https://www.roycastle.org/system/file\\_uploads/20002/original/01\\_Targeted\\_LDCT\\_Screening\\_Standard\\_2018.pdf](https://www.roycastle.org/system/file_uploads/20002/original/01_Targeted_LDCT_Screening_Standard_2018.pdf)

<sup>viii</sup> <https://www.legislation.gov.uk/ukpga/2010/15/section/20>

<sup>ix</sup> <https://rcni.com/hosted-content/rcn/first-steps/reasonable-adjustments>