

From awareness to action: Better cancer care for people with learning disabilities



Amy George RNLD- Strategic Health Facilitator
Marta Coates RNLD-Strategic Health Facilitator
Louise Bradbury RNLD-Health Facilitator
Alison Good RNLD-Health Facilitator



Health Facilitation Team-Learning Disabilities

Learning Objectives



- Recognise inequalities in cancer care for people with learning disabilities
- Reflect on clinical decision making
- Identify practical adjustments
- Reflect on how cancer care for people with learning disabilities could improve

Primary care is where uncertainty lives

- Most symptoms are benign
- Most weight loss has an explanation
- Most 'not quite right' stories resolve

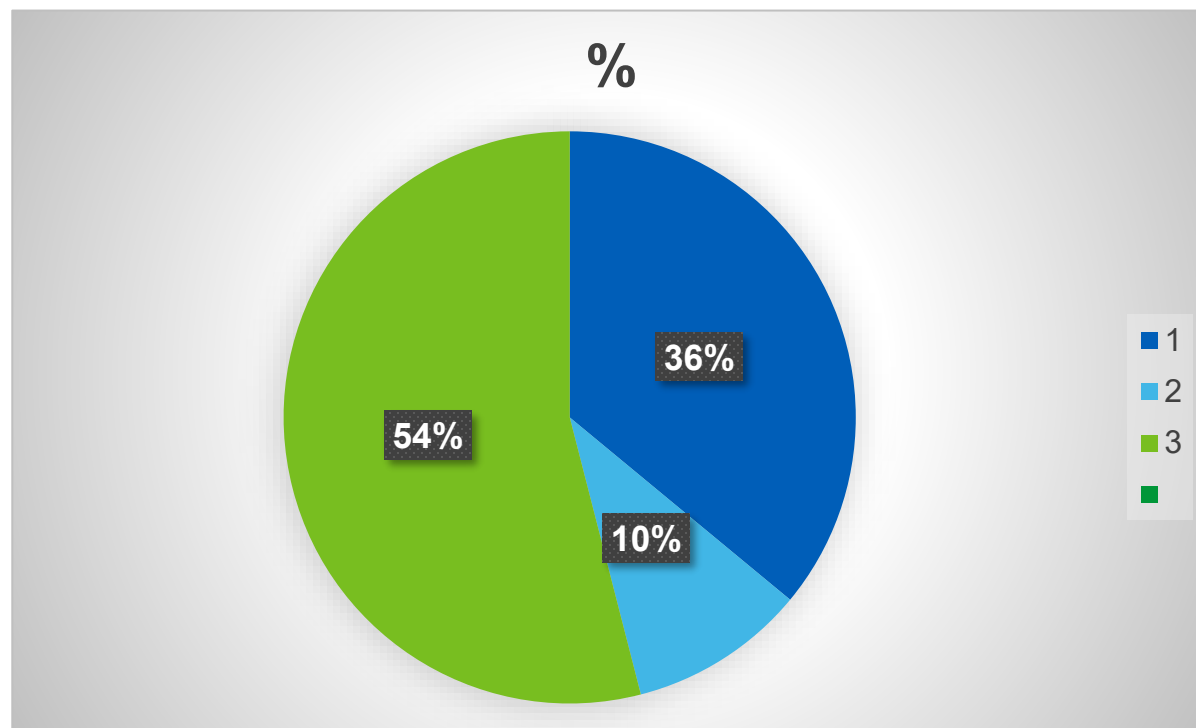
[My presentations – Mentimeter](#)

sky news

'THEY JUST KEEP FOBGING US OFF'

LeDeR Deep Dive- Cancer in learning disabilities

There were 358 adults with a learning disability who died from cancer in 2021 who had a LeDeR review and 284 in 2022 (642 in total), what do we know about these deaths;

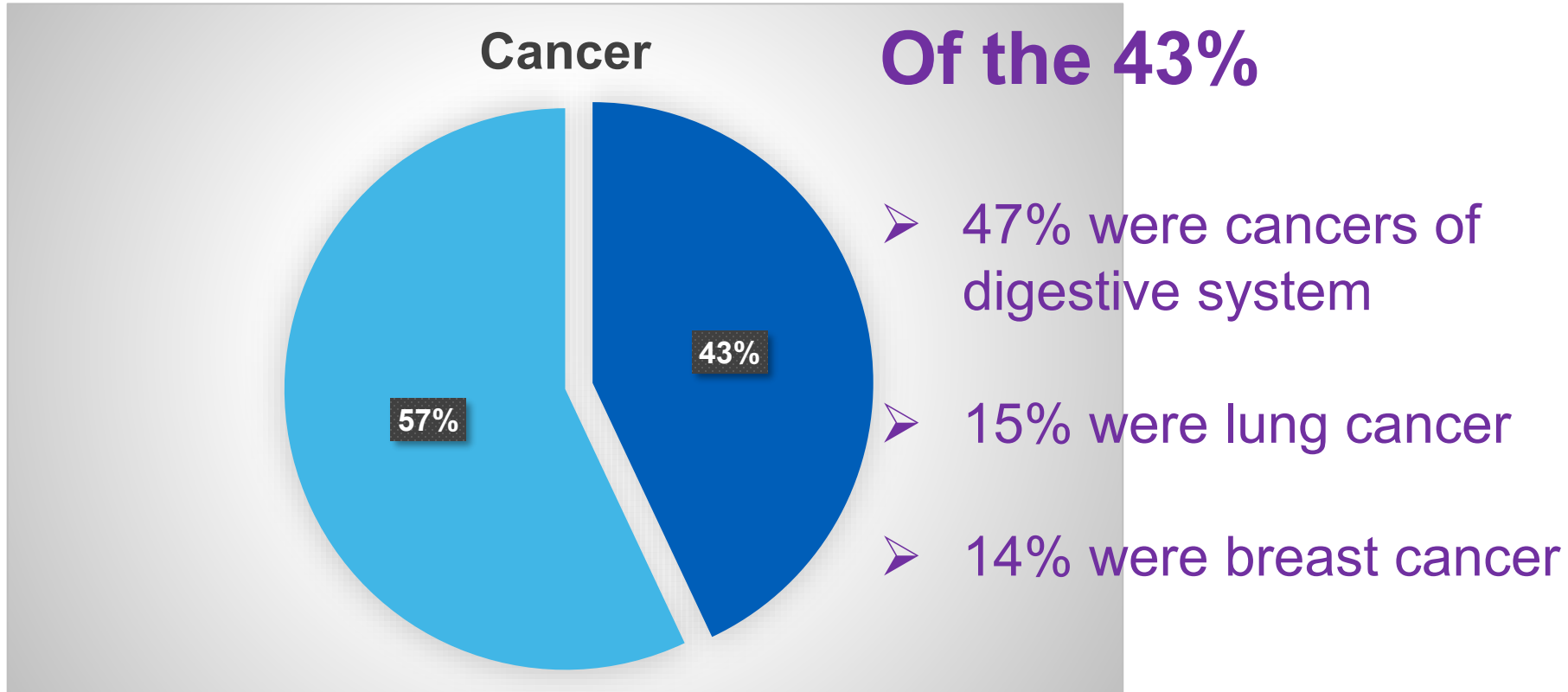


36% cancers of digestive organs

10% respiratory and intrathoracic organs

54% other

43% of the 642 deaths were classed as **avoidable**



Adults who died from an avoidable cancer were more likely to live in a Residential / Nursing home

What is the evidence telling us....

Researchers from Manchester University found that people with learning disabilities were over 70% more likely to develop cancer before the age of 50.

This pattern was especially pronounced for nervous system, uterine, ovarian and digestive tract cancers. Oesophageal cancer in the under-50s was more than five-fold higher in those with a learning disability.

A Study published by Glasgow University, in August 2024, found that adults with learning disabilities had a higher incidence of metastatic cancer of unknown primary origin (cancer that has spread to other parts of the body), and three times as many died from cancer at this advanced stage compared to the general population.

The study also found that people with learning disabilities were about half as likely to be referred for urgent investigation when they had 'red flag' symptoms that could be due to cancer.

They were more often diagnosed after the disease had spread, when a cure was not possible, and were less likely to receive surgery, radiotherapy or systemic anticancer therapy.

Life expectancy after cancer diagnosis was significantly shorter, particularly among those with severe learning disability or Down's syndrome, with most dying within four years of diagnosis, compared with nine years among those without a learning disability.

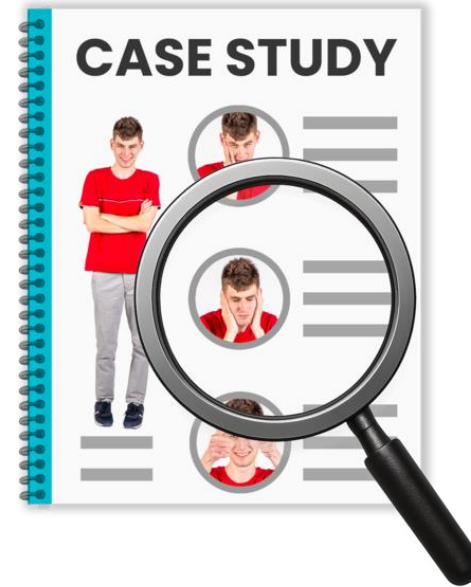
Group Task



Michael, a 52 year old man with moderate learning disabilities and limited verbal communication, lives in supported accommodation.

Over 4 months:

- ❖ Staff report he is “not himself”
- ❖ Reduced appetite
- ❖ Weight loss (5kg)
- ❖ Increasing agitation
- ❖ Intermittent abdominal discomfort
- ❖ Refusing meals occasionally



He has been seen twice in primary care and once in urgent care. Notes describe “behavioural change, likely anxiety, constipation?” He is prescribed laxatives and later low-dose antidepressants. Three months later he presents acutely unwell and is diagnosed with advanced colorectal cancer.

Discuss....

1. What went wrong?

Were there missed opportunities? Was diagnostic overshadowing present? Were red flags appropriately considered?

2. Barriers to early diagnosis

3. What would good practice look like?

Think about what tools could be used to support assessment? What role do carers have? Escalation-when? What reasonable adjustments should be made?

4. If you were the GP today, what would you do differently at first consultation, second consultation and urgent care review?



Angela Elizabeth
TER
Died 12th October
Aged 59 Years

FALLING THROUGH THE GAPS



In Angela's memory....

*How can we create clinical environments
where people with learning disabilities are
heard as clearly as everyone else?*



References

Kings College London, LeDeR 2025- Avoidable cancers, avoidable causes of death for people with a learning disability diagnosed with cancer

[Avoidable Cancer Deep Dive](#)

Manchester Study; [Cancer diagnoses, referrals, and survival in people with a learning disability in the UK: a population-based, matched cohort study](#)

Glasgow Study; [e084421.full.pdf](#)

hiowh.ldhantshealthfacilitators@nhs.net

<https://hiowhealthcare.nhs.uk/our-services/learning-disability-services>

hiowhealthcare.nhs.uk



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