



Cancer experiences of people with Learning Disabilities & the people who support them



DID YOU KNOW?

- **2% of the population in the UK have a Learning Disability. That's roughly 1 in 50 people / 1.5 million people (MENCAP, 2023).** The term 'Intellectual Disabilities' is also used in the UK but to a lesser extent.
- **In Australia, 1.8% of the population (450,000 people) have an Intellectual Disability (Australian Government Department of Health, 2021).**

POSTER QR CODE



BACKGROUND



Whilst people with Learning Disabilities are living longer (NICE, 2018):

- they have a significantly reduced mean life expectancy (White et al., 2022) & are three-times more likely to die from an avoidable medical cause of death (University of Bristol, 2021) compared to people who do not have a Learning Disability.

The incidence of cancer amongst this group is increasing (Rundle & Tunmore, 2019) & inequalities are evident:

- barriers to screening (Chan et al., 2022), advanced stage diagnoses (Heslop et al., 2022) & fewer invasive treatments (Boonman et al., 2022).

People with Learning Disabilities are often excluded from conversations about their cancer care, treatment, & support (Flynn et al., 2016; Abdulla & Spassiani, 2021). Factors that prevent inclusion include:

- Ineffective communication, Diagnostic Overshadowing, limited Reasonable Adjustments & inappropriate application of capacity legislation (Randle & Tunmore, 2019).

SCOPING REVIEW



What research exists on the experiences of people with Learning Disabilities living with & beyond cancer who navigate the cancer pathway?

- Search terms, inclusion criteria [incl. published 01/2010-08/2022 in English] & exclusion criteria applied in 9 databases. 1,114 articles screened with input from the College of Radiographers.
- 72 articles included in the Scoping Review & mapped to the cancer pathway
- Selection of key points detailed below:

Screening: Most articles indicated people with Learning Disabilities have limited insight about cancer, risks & screening. Screening enablers incl. preparedness, Reasonable Adjustments & familiar support. Screening barriers incl. pain & previous poor treatment in hospital, worry & embarrassment. Challenges: severity of Learning Disability, consent, protect vs enable.

Diagnosis & Treatment: People with Learning Disabilities are often excluded from decision-making. Tailored approaches are essential. Some professionals feel less confident supporting people with Learning Disabilities. **None of the articles focused solely on the Radiotherapy experiences & the involvement of people with Learning Disabilities who have cancer & the perceptions of stakeholders who support them.**

Breaking Bad News: Professionals often perceive family members to have an influential role in deciding whether to disclose bad news. Some family members may opt to protect their relative from bad news.

End of Life Care & Palliative Care: People with Learning Disabilities are not always involved in decision making & this may be viewed as a protective factor. Challenges are heightened when people have a severe Learning Disability.

Screening & Pre-Screening:

32 primary research articles

Diagnosis & Treatment:

5 primary research articles

19 case studies

1 systematic review with survey

1 'other'

Breaking Bad News:

4 primary research articles

End of Life Care & Palliative Care:

5 primary research articles

Other:

5 primary research articles

RADIOTHERAPY STUDY (PENDING ETHICAL APPROVAL)



An investigation of the process of Radiotherapy as perceived by people with a Learning Disability who have cancer, their family members, paid carers, & the professionals that support them: A Constructivist Grounded Theory Study.

- **Aim:** To explore multiple stakeholder perspectives & processes involved in Radiotherapy decision-making, treatment, & post-treatment support for people with Learning Disabilities who have cancer.
- **Primary Objective:** To develop a framework to optimise Radiotherapy decision-making, treatment, & post-treatment support involving people with Learning Disabilities who have cancer, as the basis for the development of practice guidelines.
- Unstructured interviews with people who have a Learning Disability & cancer, family members, paid carers, healthcare, social care & medical professionals in England & Metropolitan Melbourne, Australia.
- Advisory Group incl. representation from the Down's Syndrome Association & people with lived experiences.

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FIND OUT MORE

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MACMILLAN CANCER SUPPORT

