

People with intellectual disability are often diagnosed with cancer when it is already well advanced

October 18 2023, by Martin McMahon



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Many people with intellectual disability are diagnosed with cancer [when it has already spread](#) (metastasized) and the odds of survival are lower.

Intellectual disability is a [lifelong condition](#) that occurs before adulthood where people have a reduced ability to understand new or complex information, learn new skills and cope independently. In the UK it is called "learning disability".

Cancer has been reported as the cause of death [about 1.5 times more often](#) among people with [intellectual disability](#) than people without it. In a recent study, my colleagues and I found that cancer is the [second leading cause of death](#) in Ireland for people with intellectual disability who live in residential care homes.

Cancers tend to be found late in this cohort for a number of reasons. One of these is the [attitudes of health care staff](#), who may be influenced by stigma, previous negative experiences and communication barriers.

Other problems include underestimating the severity of a person's symptoms or assuming that the symptoms are to do with their intellectual disability rather than having a [biological cause](#). For example, if a person sees a doctor because they are self-harming, the doctor might assume that it's related to the patient's intellectual disability rather than a sign of distress caused by other symptoms they can't verbalize.

Many people in this population have a higher chance of developing cancer and having worse outcomes because they have more long-term health issues with high rates of [obesity](#), [physical inactivity](#), and [mental health issues](#). They are more likely to be [poor](#), [unemployed](#) and [lonely](#) and their housing situation also tends to be [precarious](#). Some studies have found that they are less likely to take part in cancer [screening programs](#).

People with intellectual disability often have [poor communication skills](#). This can stop them from being able to get their point across about the symptoms they are experiencing. So it is up to health care professionals

to identify signs of illness, which can be difficult.

When all these risks are combined, it is clear why people with this disability may experience delayed cancer diagnosis—or even no diagnosis at all.

Making reasonable adjustments

In England, [recent research](#) found that over 40% of adults with intellectual disability who died from [bowel cancer](#) died before they reached the age for cancer screening.

To improve [cancer care](#), [health professionals](#) need to make [reasonable adjustments](#) for this group of people. These adjustments could include screening at an earlier age, giving them longer appointments, making information accessible so they can understand it, involving them in [decision-making](#), and providing a [hospital passport](#) that includes details about their abilities and needs and [general health](#).

In England, health care professionals receive [mandatory training](#) on people with intellectual disability. The training provides an overview and awareness of the support that they need and ensures that health and social care staff have the right skills and knowledge to provide care for them.

This training on a national level is unique and could be used in Ireland and other countries to help improve health care for people with this disability.

People in this cohort are [living longer](#) but [getting](#) cancer and [dying](#) from it at a higher rate than other people. To detect cancer early and increase their chances of survival there needs to be recognition by health and care staff that this population experience greater challenges and risks and is

more vulnerable to receiving late-stage diagnosis.

Increased uptake of [cancer](#) screening, reasonable adjustments and training are urgently needed to make this situation better.

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