Policy Statement

Inequalities in cancer experienced by those with learning disabilities

Individuals with learning disabilities and health inequalities
Individuals with a learning disability sit along a spectrum and the severity of their disability will determine how much extra health information and support they require (see the background information below). For example those with a mild learning disability may only require very minimal extra support in terms of understanding health information, while those with a severe disability are likely to require round the clock assistance.

It appears that those with learning disabilities have similar incidence rates to the general population for the majority of cancers. Although the group does have higher incidence of cancers related to gallstones and oesophageal reflux; those of the oesophagus, stomach and gallbladder.¹

Research indicates that those with learning disabilities have high rates of diseases that are not being properly treated, and that they often have poor access to preventative services.² ³ Communication difficulties among those with severe learning disabilities make the occurrence of incorrect diagnosis or ‘diagnostic overshadowing’ (where symptoms are attributed to the learning disability without appropriate investigation) more likely. At the same time individuals from this group are at an increased risk of suffering from multiple health conditions, such as having a learning disability and a mental health problem. This further highlights the need for the tailoring of cancer information and services if the needs of this group are going to be met.

Women with learning disabilities have been identified as a group with consistently low uptake rates of cancer screening. Evidence indicates between 3 and 24 per cent of this group attend cervical screening.⁴ ⁵ ⁶ In terms of breast screening it appears that uptake for this group is similar to that of the general population. One issue for this group is that those with severe learning disabilities who are living in a care facility may not be individually registered with a GP and may therefore not receive invitations to cancer screening.

Next steps
In order to understand the health needs of those with learning disabilities, and provide services to meet these needs it is important to:

- Information and support should be provided in a way that fits with the intellectual capacity of the individual, this can be achieved through providing extra time with health professionals.
- The efficacy of providing easy-to-understand written and picture based information for this group should be researched.
• Health professionals should be asked about their confidence with communicating with those with learning disabilities, and further training in this area offered where appropriate. Training could also be offered to begin to break down some of the assumptions that health professionals may hold about this group.
• Although there is some evidence that those with learning disabilities have lower uptake rates of preventative services, such evidence is often from small-scale studies; further research needs to be undertaken to get a better picture of service use, and experiences of service use, among this group.
• Research should also be undertaken to explore the level of cancer sign and symptom awareness among those with learning disabilities.

Background information
There are currently three criteria used to identify if an individual has a learning disability. These are:
• Intellectual impairment
• Social or adaptive dysfunction (ranging from the ability to eat and drink to using learnt skills in different situations)
• Early onset (impairments are present in the developmental stage of life). 7

Once a learning disability has been identified the individual’s disability is then categorised as mild, moderate, severe or profound (these categories sit along a spectrum and there are no clear boundaries between them). Categorisation is often achieved through the use of an IQ assessment but may also take into account the other two factors, social or adaptive dysfunction and early onset, when determining the severity of an individual’s disability. There is no single definition of what constitutes a learning disability and because of this there are no exact figures for the number of people living in the UK with this type of disability. Current estimates range from just under 1 million 8 to around 1.5 million 9, or about 1-2 per cent of the population 10. Estimates for those with a severe or profound learning disability are more accurate, because of this group’s need for support services, and place the rate at around 0.35 per cent of the population (just under 211,000 individuals). 11

For more information contact Cancer Research UK’s Policy and Public Affairs team on 020 7061 8360 or publicaffairs@cancer.org.uk.

References
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