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The ovarian cancer support charity

Ovarian Cancer and people with learning disabilities:

A quick guide for healthcare professionals





Over 7,500 people are diagnosed with ovarian cancer each year.

There is no screening programme for ovarian cancer and signs and symptoms can be vague. It is important for people to recognise the signs and symptoms and seek advice from a doctor as soon as possible.

In the UK there are approximately 905,000 adults with learning disabilities. Studies have shown that people with learning disabilities have significantly poorer health outcomes before the age of 50 years than people in the general population. People with learning disabilities are more likely to receive a delayed cancer diagnosis. This is recognised as relating to their inequity of access to health services.



Barriers to healthcare access

Some healthcare providers may lack understanding, knowledge, and awareness about how to support people with learning disabilities, which include how to make appropriate and reasonable **adjustments**. [1]

People with learning disabilities and autistic people may face **barriers** to accessing **healthcare** which include **fear**, **understanding** and **communication skills**.

Short appointment times may not lead to **good outcomes** and may deter people from seeing the **doctor** again [2]

Some people with learning disabilities and autistic people may find **clinical environments** or **waiting rooms** **challenging**, due to **sensory triggers** like **noise**, **odours**, and **bright lights**.

Citations:

- [1] Doherty et al. Barriers and facilitators to primary health care for people with intellectual disabilities and/or autism: an integrative review. *BJGP Open*. 2020 Aug
- [2] <https://dimensions-uk.org/dimensions-campaigns/mygpandme-campaign-health-inequalities/free-training-support-healthcare-providers/getting-annual-health-checks/>

Barriers to discussing ovarian cancer

Recognising signs and symptoms of ovarian cancer is more complicated in people with learning disabilities due to potential communication barriers and symptoms being experienced in different ways.

People with a learning disability may find it difficult to explain what the problem is to a doctor.

Diagnostic overshadowing may lead to practitioners attributing distressed behaviour to a learning disability when it could be a reaction to abdominal pain, or other physical symptoms.

Not having access to adequate cancer information in appropriate formats can mean people aren't aware of the signs and symptoms of ovarian cancer or don't understand what a referral for further tests may mean.

People with learning disabilities may be left out of conversations about a cancer diagnosis, leading to further barriers in making informed decisions about any subsequent treatment and care.

Best practice

- Remember the B.E.A.T symptoms for ovarian cancer. Bloating, Eating difficulty, Abdominal pain and Toilet changes.
- Consider the environment and offer alternative waiting and appointment areas free from noise and distractions.
- Accessible information. Ovacome produces a series of EasyRead information on ovarian cancer.
- Talk to the person directly. Their support worker will help them express themselves if necessary.
- Support workers and families have expert knowledge of the person with learning difficulties. Listen to them, too, and make shared decisions.
- Ensure all staff are appropriately trained in learning disabilities.
- Offer longer appointments so that the patient has more time to process and understand information.

For further **information and support** please contact us:

- ▶ Call: 0800 008 7054
- ▶ Email: support@ovacome.org.uk
- ▶ Text or Whatsapp: 07503 682 311
- ▶ Go online at ovacome.org.uk

Call, email or text our support line, open Monday-Friday 10am-5pm

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