

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

In partnership with:



www.dimensions-uk.org



Registered Charity Number: 1159682