

Preventing deaths of people with disabilities in care

Information for staff of disability services



The NSW Ombudsman's office reviews the deaths of people in disability accommodation services and makes recommendations to reduce preventable deaths.

Preventable deaths

On average, people in **disability services die around 25 years younger** than the general population.



The main causes of death include:

- **Respiratory diseases** – mainly aspiration (breathing food or fluid into the lungs), pneumonia, chronic obstructive pulmonary disease (COPD) and asthma.
- **Heart diseases** – mainly ischaemic heart diseases, including blocked arteries of the heart and heart attack.
- **Choking on food** – due to swallowing or eating problems, such as eating quickly, eating without chewing, and overfilling the mouth.
- **Epilepsy** – mainly due to breathing fluid into the lungs during a seizure.
- **Cancers** – mainly bowel cancer and lung cancer.

Many of these deaths are preventable.

Below are some of the key things you should know to avoid preventable deaths and improve the health of the people you support.

If you support someone who...

a) has problems with eating, swallowing, breathing or moving around

They may be at risk of death from respiratory disease, or from choking on food. Look out for people with the following risks:

- **feeding and swallowing problems** (including difficulty sitting upright, and reliance on others to be fed)
- **eating problems** (such as eating too quickly, without chewing, or with too much food in the mouth)
- **frequent chest infections**
- **drowsiness or reduced alertness**
- **mouth or dental problems**, including gum disease
- **gastrointestinal problems**, such as reflux or vomiting
- **medication side effects**
- **cerebral palsy, Down syndrome or epilepsy**
- **problems moving around**

Help them to get support.

For more information about what you should do, see our factsheet 4: *Breathing, swallowing and choking risks*.

b) smokes, is overweight, has a poor diet, or lacks physical activity



They may be at risk of death from heart disease, lung cancer or bowel cancer. Look out for people with the following risks:

- **smoking**
- **high 'bad' cholesterol**
- **high blood pressure**
- **diabetes**
- **lack of exercise**
- **obesity**
- **lack of fruit and vegetables in their diet**
- **depression**
- **bowel problems** or a family history of bowel cancer

Help them to get support.

For more information about what you should do, see our factsheet 5: *Smoking, obesity and other lifestyle risks*.

c) takes multiple medications, or takes medication for behaviour management or to treat mental illness



Many people in disability services take medications that can have serious side effects, including drowsiness, confusion, obesity, and increased risk of falls and choking on food.

People in disability services can also be at risk of health problems or death from toxic levels of medication (either from toxic levels of one medication or from a combination of medications).

Because of the risks of bad side effects and the need to get the level of medication right, YOU MUST provide support to people with disabilities to access regular medication reviews by their GP and/or their psychiatrist. You should also support people with disabilities in getting regular expert assessments on whether behaviour management support should be used instead of, or in conjunction with, medication.

Other things you must do: disability support workers

It is important that you:

➤ Know the person that you support

- **Know what support the person needs and what you need to do to help them.** Some people need specific support to stay healthy and well (such as making sure food is safe to swallow), and it is critical that they get that help.
- **You need to be able to tell if the person you support is sick or needs help.** You need to understand how the person communicates, and how you can help them to do this. For some people, communication may involve gestures, body language, pictures, signs or sounds.

➤ Take action

- **Look out for any changes in the person's health or behaviour**, such as swallowing problems, falls, drowsiness, unexplained weight loss, pain, and sleeping problems. Talk with your manager about the changes, and help the person to see their GP as soon as possible.
- **Get medical help without delay.** We have found that some people with disabilities die very soon after showing signs of illness. If you're not sure, always get medical help, and make sure you know what to do in an emergency.
- **Always follow the advice and recommendations of doctors and other health care providers.** If you're not sure what to do, ask your manager or the person's GP.

Other things you must do: managers in disability services

It is important that you:

- **Use staff supervision and team meetings** to reinforce the information in our factsheets about key risk factors and what disability support workers can do to reduce preventable deaths.
- **Ensure that staff receive a comprehensive induction** when they start, and that the guidance that is available to them is clear and up-to-date.
- **Regularly check staff practice against requirements** (including medication administration, risk management, and follow-up of healthcare recommendations). If there are any problems, identify what the barriers are and what you need to do in response.
- **Make sure that action is taken following an incident or 'close call'** to prevent it from happening again.
- **Work together with the person with a disability and health services** to help the person to access the health care and treatment they need, and to obtain appropriate support in hospital.

Resources and further information

Reviewable deaths

- For more information, see our *Report on Reviewable Deaths in 2010 and 2011* (May 2013), at www.ombo.nsw.gov.au
- *Preventing deaths of people with disabilities in care* factsheets:
 - *Factsheet 3: Information for General Practitioners*
 - *Factsheet 4: Breathing, swallowing and choking risks*
 - *Factsheet 5: Smoking, obesity and other lifestyle risks*

Health care and people with intellectual disability

- NSW Council for Intellectual Disability Healthier Lives fact sheets, at www.nswcid.org.au

Contact us for more information

Our business hours are: Monday to Friday, 9am–5pm (*Inquiries section closes at 4pm*). If you wish to visit us, we prefer you make an appointment. Please call us first to ensure your complaint is within our jurisdiction and our staff are available to see you.

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We can arrange an interpreter through TIS or you can contact TIS yourself before speaking to us.

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