

# Preventing deaths of people with disabilities in care

## Information for General Practitioners



The NSW Ombudsman reviews the deaths of people with disabilities in care (disability accommodation services and licensed boarding houses), and makes recommendations to reduce preventable deaths.

### Preventable deaths

General Practitioners play a vital role in identifying and supporting the health needs of people with disabilities and avoiding preventable deaths.



### Main causes of death



On average, **people with disabilities in care die between 15 and 25 years younger than the general population.**

#### The main causes of death include:

- **Respiratory diseases** – mainly aspiration, pneumonia and chronic lower respiratory diseases such as COPD
- **Heart diseases** – mainly ischaemic heart diseases
- **Cancers** – mainly lung cancer and bowel cancer
- **Digestive system diseases** – including volvulus, acute intestinal vascular disorders, and megacolon
- **Choking on food**

## Key risk factors

People with disabilities are susceptible to death from the causes on the previous page due to multiple risk factors.

In particular, they face significant risks relating to:

- **problems with swallowing and eating**
- **smoking, obesity, poor diet and insufficient physical activity**
- **recurrent respiratory infections and lung disease**
- **chronic health problems**, such as gastro-oesophageal reflux disease (GORD), constipation, diabetes and hypertension
- **conditions such as cerebral palsy, epilepsy, and Down syndrome**, and
- **multiple medications, including psychotropic medications**

## What you can do

Our reviews have emphasised the critical role GPs can play in reducing preventable deaths of people with disabilities, through:

- **Undertaking comprehensive health assessments and regular medication reviews**
- **Providing clear guidance about recommendations and necessary actions**
- **Providing proactive help to quit smoking** through access to smoking cessation programs and provision of nicotine replacement therapy
- **Referring people with disabilities to specialists and health programs** – especially for respiratory issues and chronic disease management
- **Working with people with disabilities, disability services and health providers** to provide proactive support to address the modifiable risk factors associated with respiratory disease and heart disease
- **Considering the need for influenza and pneumococcal vaccination**

Each year, we review the deaths of around 100 people with disabilities in care. Our reviews over the past 10 years have identified critical actions that can improve the health of people with disabilities and reduce preventable deaths.

On the next page are some of the most critical issues to consider.

# Key messages from our reviews

## Comprehensive health assessments

Our reviews have emphasised the importance of comprehensive assessments of the health of people with disabilities.

These assessments include MBS items relating to the annual health assessment of people with intellectual disability; and to chronic disease management and team care arrangements.

While the number of people with disabilities with a comprehensive health assessment has increased, there continue to be those who have never had a full health review. This is particularly the case for boarding house residents.

We have found that people with disabilities and the staff supporting them are highly reliant on the advice and instructions of GPs. It is vital that they receive clear and practical guidance in what they need to do, and when they need to do it.

## Access to specialists

We have found low rates of specialist involvement in the care of people with disabilities with complex and chronic health problems.

This includes infrequent referral to respiratory specialists for people with chronic respiratory issues such as COPD and recurrent aspiration pneumonia.

## Access to out-of-hospital support for people with chronic diseases

We have found that people with disabilities who have chronic diseases do not tend to be referred to chronic disease management or other out-of-hospital programs.

This includes people who meet the benchmark of 'high risk' or 'very high risk' patients, and who have multiple presentations to hospital for their chronic illnesses (including COPD, coronary artery disease, chronic lung disease and diabetes).

## Smoking and boarding house residents

Smoking is a significant risk factor for people in licensed boarding houses. Their smoking rate is much higher than the general population, and they tend to be heavy smokers.

Of the residents who died in 2010 and 2011, 88% had smoked, including all of the people who died from lung cancer, pneumonia, COPD, and most of those who died from ischaemic heart disease.

Despite the high rates of smoking, our reviews have found that boarding house residents are rarely linked to proactive quit smoking strategies, such as the provision of nicotine replacement therapy.

## Importance of teamwork

Our reviews have highlighted the importance of teamwork between GPs and other relevant health providers, the person with a disability, and the staff that support them.

We have found that some people with disabilities have missed out on critical medical treatment because of their behaviour and aversion to health examinations and other interventions, and hospitals.

GPs can play a key role in helping people with disabilities to overcome their aversion and resistance, and to make it easier for them to get the treatment they need. It is important that GPs work together with the person with a disability and their support staff to identify ways to do this.

Staff supporting people with disabilities can help them to communicate and to provide valuable health information about their medical history and recent changes. They are also important in helping to make sure the recommendations of GPs are followed.

## Further information

For more detailed information, see our *Report on Reviewable Deaths in 2010 and 2011* (May 2013), and our other reports on reviewable deaths, at [www.ombo.nsw.gov.au](http://www.ombo.nsw.gov.au).

For information on healthcare and people with intellectual disability, see factsheets by the NSW Council for Intellectual Disability at [www.nswcid.org.au](http://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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