



Australian Government



# COVID-19 vaccination decision guide for people receiving palliative care and/or end-of-life care

Version 2

15 September 2021

*What's changed:*

*The newly registered Spikevax COVID-19 vaccine (Moderna) has been included in this advice.*

The Department of Health will publish updated versions of this guide as more information and new vaccines become available.

Please note:

- Spikevax COVID-19 vaccine (Moderna) will be referred throughout this guide as Moderna
- Comirnaty COVID-19 vaccine (Pfizer) will referred throughout this guide as Pfizer
- Vaxzevria COVID-19 vaccine/COVID-19 Vaccine AstraZeneca (AstraZeneca) will referred throughout this guide as AstraZeneca

This decision guide is to help a person receiving palliative or end-of-life care, or their caregiver, make an informed decision about getting a COVID-19 vaccine. People who have life-limiting illnesses should consider COVID-19 vaccination.

This guide currently includes information about the COVID-19 vaccines Pfizer, Moderna and AstraZeneca. Pfizer and Moderna are registered for use in people aged 12 and above. AstraZeneca is registered for use in people aged 18 and above. Pfizer and Moderna are the preferred vaccine brands for people under 60 years of age in Australia.

### **What is palliative care and what is end-of-life care?**

- Palliative care is treatment, care and support for people who are living with a life-limiting illness.
- A life-limiting illness is one that has no cure and which will therefore shorten a person's life. Such illnesses can include, but are not limited to:
  - cancer
  - motor neurone disease
  - end-stage kidney disease
  - dementia
  - neurodegenerative diseases
  - some heart diseases such as heart failure, and
  - some lung diseases such as chronic obstructive pulmonary disease.
- End-of-life care refers to the care and services given to people facing the end of their life, usually the last 12 months of life. End-of-life care is an important part of palliative care.
- Both palliative and end-of-life care are for people of any age, including children, adolescents, adults and the elderly.

### **What are the risks from COVID-19 in people receiving palliative or end-of-life care?**

Many people who are receiving palliative or end-of-life care will have a high risk of becoming seriously unwell if they get COVID-19. This is because they are likely to fall into one or more of the following high-risk groups:

- older adults – about 1 in every 3 people over the age of 80 years who get COVID-19 will die from it
- people with multiple medical conditions, or medical conditions that are not well controlled
- people with weakened immune systems (immunocompromise)
- people with cancer, particularly blood cancer or lung cancer, and those having chemotherapy or radiotherapy.

Having COVID-19 may also disrupt the person's care plans. For example, it may be hard for the person with COVID-19 to receive care or have visitors.

- For more information about which medical conditions increase one's risk of severe illness from [COVID-19: Advice for people at risk of coronavirus](#) (COVID-19)
- For more information on risks for older people with frailty: [COVID-19 vaccination decision guide for frail older people, including those in residential aged care facilities](#)

## Are COVID-19 vaccines effective in people receiving palliative or end-of-life care?

- COVID-19 vaccines have not yet been trialled in people receiving palliative or end-of-life care, or people with unstable medical conditions or weakened immune systems. This is because clinical trials for new vaccines start with young healthy volunteers. COVID-19 vaccines may be less effective in people who have weakened immune systems and people with unstable medical conditions.
- Results from the COVID-19 vaccine programs in Scotland and England on Pfizer and AstraZeneca suggest that both vaccines are very effective at preventing serious illness in people aged 65 years and older. People in this age group who had a COVID-19 vaccine were much less likely to be hospitalised due to COVID-19. Similarly, results from the vaccine program in a large part of Canada suggest that Pfizer and Moderna are very effective at preventing COVID-19, as well as preventing hospitalisation and death due to this disease.
- A large clinical trial of Pfizer included older adults aged 65 years and over. The large clinical trial for Moderna also included adults aged 65 years or over; this was about one quarter of all participants. Both trials showed the vaccine to be very effective and safe in this age group. The clinical trials for AstraZeneca also included older adults and showed efficacy in this age group, but full results are not yet available.
- The Pfizer vaccine provides partial protection against COVID-19 from as early as 12 days after the first dose. People should receive their second dose about 3 weeks later. This is important for optimal protection.
- The Moderna vaccine provides partial protection against COVID-19 from 14 days after the first dose. However, people should receive the second dose about 4 weeks later as this is important for optimal protection, and to prolong the duration of protection.
- The AstraZeneca vaccine provides protection against COVID-19 from about 3 weeks after the first dose. People should receive their second dose about 12 weeks later, however can receive the vaccine as soon as 4 weeks later, if required.

## Are COVID-19 vaccines safe in people receiving palliative or end-of-life care?

- The clinical trials for Pfizer, Moderna), and AstraZeneca did include people with chronic medical conditions, but did not include people who:
  - were receiving palliative or end-of-life care, or
  - who had unstable medical conditions or weakened immune systems.
- As of August 2021, there have been over 4.5 billion doses of COVID-19 vaccine given to people around the world. This includes people in residential aged care facilities, and people with medical illnesses, who have been prioritised for vaccination in many countries.
- The clinical trials for Pfizer, Moderna, and AstraZeneca included older adults aged 65 years and older, up to about 90 years of age. All three vaccines were safe and well tolerated in this age group. Also, older adults had fewer side effects than younger adults.
- Pfizer, Moderna, and AstraZeneca are currently being tested in children. Pfizer and Moderna can only be given to people aged 12 years and older. AstraZeneca can

only be given to people aged 18 years and older. There are currently no COVID-19 vaccines available for use in children under the age of 12 years.

- There were reports of deaths occurring overseas in older people in aged care facilities after a COVID-19 vaccine dose. This was investigated and it was found that receiving COVID-19 vaccine did not make dying more likely. The deaths were thought to have occurred because of the age or health of the person.
- A very rare side effect involving blood clotting with low blood platelet count may occur with the COVID-19 Vaccine AstraZeneca. The name of this condition is thrombosis with thrombocytopenia syndrome (TTS). It appears to be less likely in older adults than in younger adults, but is very rare. For older persons, the benefits of protection against severe COVID-19 through vaccination greatly outweigh the risk of harm from this very rare condition. There is no evidence that people with immunocompromised or receiving end-of-life care have a higher risk of TTS. Pfizer and Moderna are not associated with a risk of TTS.
- People under 60 who cannot readily access Pfizer or Moderna can still have the AstraZeneca vaccine if the benefit of vaccination is likely to outweigh risk, and where informed consent has been obtained. This is particularly important for people who have medical conditions that increase their risk of severe COVID-19.
- For more information about TTS, refer to the [patient information sheet on AstraZeneca COVID-19 vaccine and TTS](#).

### What are the side effects of Pfizer?

- People getting Pfizer will likely have some mild side effects for a day or so after the vaccine. The most common side effects are injection site pain, fever, tiredness and headache:
  - Pain at the injection site is very common, occurring in about two thirds of people.
  - Up to 1 in 9 people aged 55 years or older will have a fever for 1–2 days, more commonly after the second dose. The fever is usually mild to moderate and goes away after 1–2 days.
  - About 1 in 3 people will have side effects such as tiredness and headache. These most commonly begin 1–2 days after getting the vaccine and go away after around 1–2 days.
  - Fewer than 1 in 40 people will have a fever above 40°C
  - In clinical trials, fewer than 1 in 20 people experienced any severe side effect. Any side effects were generally more frequent after the second dose, and less frequent in adults aged 55 years and older.
- Side effects are milder and less common in older adults (aged 55 years and over) than younger adults.
- Most people who have these side effects can still carry on their usual daily activities. Less than 1 in 4 people may experience tiredness that lowers their ability to carry out daily activities. 1 in 40 people may have tiredness severe enough to prevent their daily activities, for up to a few days.
- Anaphylaxis, a rare but severe type of allergic reaction, can occur after receiving any vaccine. Experience in the USA showed the chance of an adult having anaphylaxis after the Pfizer vaccine was about 1 in every 200,000 people vaccinated.
- Very rarely, myocarditis (inflammation of the heart muscle) and pericarditis (inflammation of the outer lining of the heart) can occur following vaccination with the Pfizer. Most reported cases have been mild, self-limiting and recovered quickly.

It has predominantly occurred after the second dose and predominantly in younger males (aged <30 years).

- For more information refer to [Information on COVID-19 Pfizer vaccine](#).

### What are the side effects of Moderna?

- People who receive Moderna are likely to have some mild side effects for a day or three after the vaccine. The most common side effects are injection site pain, tiredness, headache and muscle pain:
  - Pain at the injection site is very common, occurring in about two thirds of people after the first dose, almost 9 out of 10 of people after the second dose of the vaccine.
  - Fatigue, headache and muscle pains occur in about 6 in every 10 people who receive the vaccine, mostly after the second dose. These symptoms are usually mild to moderate, start within two days after the vaccine, and resolve within 2-3 days.
  - Less than 1 in 100 people experience a fever after the first dose, and about 15 in 100 after the second dose. This fever is mostly mild to moderate and resolves after 1-2 days.
    - Fever over 39°C occurs in 1 in 100 after the second dose, and fever over 40°C in less than 1 in 1000 people.
  - Severe side effects, where people were unable to carry out their normal daily activities, were seen in about 1 in 6 people after receiving the second dose.
- In the clinical trial, side effects were less common in people aged 65 years or older than in younger people. The side effects were also milder.
- Most side effects are mild or moderate, start the day of vaccination or the day after vaccination, and resolve in about 2-3 days.
- Anaphylaxis, a severe and life-threatening allergic reaction, after Moderna is very rare. In the United States, about 2.5 in every million people who received Moderna experienced anaphylaxis.
- Very rarely, myocarditis (inflammation of the heart muscle) and pericarditis (inflammation of the outer lining of the heart) can occur following vaccination with the Moderna. Most reported cases have been mild, self-limiting and recovered quickly. It has predominantly occurred after the second dose and predominantly in younger males aged <30 years.
- For more information refer to [Information on COVID-19 Moderna vaccine](#).

### What are the side effects of AstraZeneca?

- People getting AstraZeneca will likely have some mild side effects which appear within day or so after the vaccine. These usually go away within a few days. The most common side effects are pain and tenderness at the injection site, tiredness, headache and flu-like symptoms.
  - Pain at the injection site is very common, occurring in about two thirds of people

- About 1 in 3 people will feel 'feverish' or have chills, and 1 in 10 will have a fever of 38°C or higher
- About 1 in 2 people will have a headache
- About 4 out of 10 people will have muscle pain
- About 1 in 4 people will have joint pain.
- Some people may find it difficult to carry out their usual activities for a day or so after vaccination
- Side effects are milder and less common in older adults (aged 65 years and over) than younger adults.
- Side effects are milder and less common after the second dose than after the first dose.
- Anaphylaxis after AstraZeneca is very rare. The rate in Australia appears similar to any other vaccine.
- Rarely, TTS has been observed following AstraZeneca. TTS is a rare side effect that can be very serious and can cause long-term disability and death.
- For more information refer to [Information about COVID-19 AstraZeneca Vaccine](#).

### **Should I have a COVID-19 vaccine if I am receiving palliative and/or end-of-life care?**

- If you or someone you care for has an unstable medical condition or is very frail, you can discuss the appropriateness and timing of vaccination with your healthcare provider. If you are close to the end of your life, you may have many things to consider when deciding whether to have the COVID-19 vaccine. There will be different considerations for each person.

### **Possible benefits of vaccination**

- Being vaccinated will protect you against serious illness from COVID-19. COVID-19 is a serious illness which can cause death.
- People with COVID-19 need to remain in isolation until they recover. Being vaccinated will reduce your risk of getting COVID-19. This will therefore reduce the risk that you might need to isolate from your loved ones if you did get infected with COVID-19.
- Being vaccinated may also help you protect your family, carers and others around you from being infected if you were exposed to COVID-19. For example, if you are in a residential aged care facility, disability accommodation or in a hospital. A residential care facility may want as many residents as possible to be vaccinated to reduce the chance of spreading COVID-19.

### **Possible harms of vaccination**

- You may experience some side effects after vaccination, such as fever, chills, headache, tiredness or muscle pain. These side effects may temporarily affect your ability to carry out daily activities.
- These side effects could have a negative impact on your quality of life for a short period of time (usually less than 24 hours).
- Very rare risk of serious side effects.

### Other things to consider

- Your preferences regarding treatment, which you may already have considered in an advance care directive or similar care plan. The vaccine is an optional preventative treatment, and this may not be a priority for you at this time.
- You can encourage your carers and loved ones to get vaccinated when they have the opportunity. This might also provide some indirect protection to you.

### Children in palliative care

- Pfizer and Moderna are provisionally approved for use in people aged 12 years or older, and cannot be given to younger people.
- AstraZeneca is registered for use in people aged 18 years or older, and cannot be given to younger people.
- In children aged 12-17 years, Pfizer and Moderna have been shown to be very effective at preventing COVID-19, as well as at preventing hospitalisation and death due to COVID-19.
- Children in palliative care may have conditions that increase their risk of severe COVID-19, for example, immunocompromise due to cancer treatment.
- Visit the Department of Health's website [Health.gov.au/covid19-vaccines](https://www.health.gov.au/covid19-vaccines) for more information.