

# Information for patients about their data

## OVERVIEW

The Voluntary Assisted Dying Review Board (**the board**) is committed to protecting the privacy of all individuals who access voluntary assisted dying in Victoria.

The board is a statutory body established to monitor all activity under Victoria's new voluntary assisted dying legislation and to receive copies of all forms that are required under the *Voluntary Assisted Dying Act 2017* (**the Act**). Safer Care Victoria (**SCV**), provides administrative support for the board. . SCV works closely with the board and the Department of Health and Human Services (**the department**) to ensure the privacy of all individuals is maintained.

The Voluntary Assisted Dying Portal (**the portal**) is an electronic platform through which the forms and permit applications required to access the service are completed and submitted by your medical practitioner. The forms are submitted to the board.

The board and SCV collect and handle personal and health information about patients for the purposes of enabling individuals to access voluntary assisted dying as required and authorised by the Act, in line with relevant privacy and record keeping laws. Your personal information is collected by the board when the forms are submitted through the online portal.

## INFORMATION COLLECTED THROUGH THE PORTAL

The portal allows medical practitioners to complete and submit the forms required under the Act. To do this, your doctor will create a profile for you in the portal. Your profile will include mandatory information required under the Act, such as your name, date of birth and address.

If you wish, you can provide extra information such as the language you speak at home and the type of accommodation that you live in, to help the board learn more about the patients that access voluntary assisted dying.

Your doctor will provide the board with health information about you that is required in the Act, such as information about your diagnosis and prognosis. The Written Declaration Form and the Contact Person Appointment Form that you will complete will be provided to the board through the portal by your doctor.

## HOW YOUR INFORMATION WILL BE USED

Information about you that is submitted through the portal will be accessed and used by:

- your co-ordinating medical practitioner and consulting medical practitioner
- the board and SCV, to review all voluntary assisted dying cases in Victoria
- the Secretary of the Department of Health (or their delegate), to process a permit application to give you a voluntary assisted dying medication
- pharmacists at the statewide pharmacy service, to dispense you a voluntary assisted dying medication.

SCV will share the name, date of birth and address of all patients who receive a permit for a voluntary assisted dying medication to Births, Deaths and Marriages Victoria. This is to enable the identification of individuals who are deceased and hold a permit for a voluntary assisted dying medication. The board has a responsibility to contact the appointed contact person to ensure the return of any unused medication.

The board will use de-identified, collated information about patients in the reports they release to the Victorian Government and the public about voluntary assisted dying activity in Victoria.

Your information will also be used by the board for quality improvement and research purposes. Any information shared with researchers will be de-identified.

In limited situations, the board may also disclose information about you to other bodies such as the Coroner's Court of Victoria, Victoria Police and the Victorian Civil Administration Tribunal.

## **HOW YOUR INFORMATION WILL BE STORED**

The Victorian Government takes the security of your information very seriously. All efforts have been taken to ensure that the portal is secure and to protect the data and privacy of individuals. Only people required to view your information are authorised to access it. Many security features have been built into the portal to ensure the information held by the board is secure.

## **ACCESSING YOUR DATA**

Your medical practitioner will be able to inform you about what information they have provided to the board about you. You can request a copy of the voluntary assisted dying forms submitted to the board from your medical practitioner.

We will not be able to delete any information that is submitted about you through the portal, even if you decide that you don't want to continue your voluntary assisted dying request. This is because the board must store the health information that it receives about all voluntary assisted dying cases, even those that do not proceed, for a minimum of seven years.

If you wish to contact the board, you can email the secretariat of the board at [VADBoard@safercare.vic.gov.au](mailto:VADBoard@safercare.vic.gov.au).

You can also write to us at:

Voluntary Assisted Dying Review Board  
Care of Safer Care Victoria  
Level 3, 50 Lonsdale Street, VIC 3000.

## **PRIVACY QUESTIONS OR COMPLAINTS**

For more information on how the board and SCV collect, use, share and manage your personal information and handle privacy complaints, please refer to SCV's privacy policy available at <https://bettersafercare.vic.gov.au/privacy> or email [privacy@safercare.vic.gov.au](mailto:privacy@safercare.vic.gov.au).

For more about how the department collects, uses, shares and manages your personal information and handles privacy complaints, please refer to its privacy policy at <https://dhhs.vic.gov.au/privacy-statement> or email [privacy@dhhs.vic.gov.au](mailto:privacy@dhhs.vic.gov.au).