

SECTION 5: CONSENT - IT IS YOUR CHOICE

THE PURPOSE OF CONSENT

Your agreement is needed before a doctor, clinician, pharmacist or anyone looking after you examines or treats you. We call this agreement your 'consent'. Sometimes you can say that you consent to what we need to do. We call this 'oral consent'. For example, if we need to take your blood pressure or examine your throat or take some blood samples, you might say 'yes' or 'OK' to confirm your consent. At other times, we need you to sign a form to confirm your consent. We call this 'written consent'. For example, you'll be asked to give written consent, by signing a consent form, to have your chemotherapy, immunotherapy or supportive care given at home with View Health - chemo@home.

What should I know before giving my consent to have my chemotherapy, immunotherapy or supportive care at home with View Health - chemo@home?

You must understand:

- what is to happen and why;
- the choices;
- the risks;
- the benefits; and
- your responsibilities.

This information will be explained to you. We will discuss any choices you need to make, with their risks and benefits. You will be given information about your treatment.

If you would rather not know about certain things, say so. Some people prefer not to know all the details, but it's important that you understand broadly what is to happen and why, so you can give proper consent. Also, say if there's anything you don't want to happen during the treatment.

SHOULD I ASK QUESTIONS?

It's important that you understand what is happening and why. If one of our team doesn't know the answer to your question, they'll find someone else to explain. Our team will answer your questions in an appropriate timeframe, depending on the complexity and urgency of your question. Sometimes it helps to have a friend or relative present so you can talk it over later. You may like your friend, relative or someone else to speak for you. If you have hearing problems or don't understand English very well, let us know, and we will arrange for an interpreter.

QUESTIONS TO ASK

As well as giving you information, we must listen to you and do our best to answer your questions. Some examples of questions you may want to ask are:

- What are the benefits of having my treatment at home?
- What are the risks of having my treatment at home?
- Can I work during treatment?
- Will having treatment at home affect my family?

WHO IS INVOLVED IN MY TREATMENT?

You will remain under the care of your doctor while receiving treatment at home. Our highly experienced clinicians will visit you to administer your treatment and provide any additional care you may need.

There may also be times when we ask you to attend a health care facility (for example, a hospital or day unit) to receive further care. Such care may include administration of blood products or review by a doctor. If you become unwell at home, it may be necessary for you to attend the emergency department of a health care facility for treatment. It is important that you understand your responsibilities regarding attending a health care facility when it is necessary.

CONFIDENTIALITY

Because information on your treatment (clinical notes, blood tests, scans, etc.) may be kept by several different health care services or facilities, it is important that we are able to access the information we need to make sure your care can be given safely. We also need to share clinical information about your care with your medical team and other health care professionals as necessary so they may make appropriate decisions about your care. Information about your care will always be kept in strict confidence by our staff for viewing by authorised people only.

ADVANCE CARE PLANNING

As part of your care, we ask whether you have an Advance Care Directive or similar document that outlines your wishes for future health care, particularly if you were ever unable to speak for yourself. If you do have one, you are welcome to send us a copy so we can record it in our electronic health record. This allows our team to be guided by what matters most to you.

If you do not have an Advance Care Directive, that is completely okay. Some people find it helpful to learn more or reflect on this in their own time. A trusted, Australian Government-supported resource is Advance Care Planning Australia, which provides clear, compassionate information and state-specific guidance; you can visit www.advancecareplanning.org.au to explore whether this is something that feels right for you.

PHOTOGRAPHS, AUDIO OR VIDEO RECORDINGS?

Photographs, audio or video recordings may be made during your treatment. You will be told in advance if this is going to happen. Images or recordings made as part of your care and treatment will be held in your clinical record. If you can be identified from them, then only those involved in your care, or those who need to check the quality of care, will be allowed to see them without your consent. Sometimes we make images and recordings for teaching and research only. If you can be identified from them, we will always ask for your written consent before using them.

RESEARCH

View Health - chemo@home conducts research to improve our understanding of cancer treatments and to find better ways to deliver cancer treatments. We do this through:

- Accessing and reviewing specific health information about you (for example, your blood results or any complications from your treatment)
- Asking you questions about your treatment (for example, by asking you to fill in a questionnaire).

We may also collaborate with other facilities for research purposes. We will only do this if we can ensure all necessary ethical and privacy safeguards are in place.

The research conducted may be published in medical journals or presented at scientific meetings in the future, but you will not be identified in any publications. The results of any research may not benefit you directly. It is more probable that the information will be used to help guide decisions for patients in the future.

Any research we do will be approved by a Human Research Ethics Committee certified by the National Health and Medical Research Council, if required. This Council is responsible to the Commonwealth Minister for Health and Ageing. You are not obliged to give your consent to be involved in research.

REMEMBER...

It's up to you to give consent. You can change your mind at any time, even after signing the consent form. Ask as many questions as you like and tell us about anything that worries you.

If you have any concerns or questions about View Health - chemo@home, please talk to your treating doctor or contact us at:

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