



Understanding your medical condition and your treatment options is critical to making an informed choice about your medical treatment.

If medical personnel and/or health care professions do not understand any detail of your condition or your treatment, they should ask you questions and seek further information.

This pamphlet addresses conditions that have confirmed diagnoses, not conditions where a diagnosis has not yet been reached.

Genetic and Rare Disease Network (GaRDN)

GaRDN works to ensure that people with genetic and rare diseases have timely access to relevant, up-to date information about their condition and the healthcare and other services available to them in WA. GaRDN represents the collective voices of people with genetic and rare diseases, their families and carers, to ensure that they are included in health policy and strategic decision making. GaRDN aims to make health professionals more aware of genetic and rare diseases. GaRDN works to develop integrated, coordinated health care and support by stakeholders involved in the support and health care of people with genetic and rare diseases, their families and carers.

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Treatment of rare medical conditions

- In emergencies
- Consent Issues

Promoting awareness and understanding of genetic and rare diseases

Individuals with rare medical conditions may seek emergency medical care from doctors who know very little about their condition.

People with rare medical conditions can become experts in the signs, symptoms and treatments for their condition, including:

- when to seek treatment
- the urgency of their need
- treatment that have been successful in the past, and
- treatments that have not worked

Issues for patients

Issues may arise for a patient when their rare medical condition needs to be treated in an emergency. This may include:

- knowing what you need, but not having the power to access it
- concern about your judgments and views not being believed
- fears of the potential consequences of not being treated

Issues for doctors

Issues for treating doctors, responding to an urgent need of a person with a rare medical condition may include:

- not knowing what treatment to offer
- being asked to trust the patient's judgment
- concern about their responsibility if something goes wrong

What patients can do

When seeking emergency medical treatment patients with a rare medical condition can:

- provide any brief and informative documentation that you may have about your condition
- provide contact details of your specialist (if applicable)

What doctors can do

What doctors can do when treating a rare medical condition in an emergency:

- give credence to the information offered by the patient about their condition
- be prepared to contact specialists for advice

For further information:

Genetic and Rare Disease Network (GaRDn)

Phone: 1300 770 995

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Health Consumers' Council

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Consent to treatment for a rare medical condition

Usually consent is sought for treatment proposed by a doctor, and is then agreed to by a patient.

Individuals with rare medical conditions may find themselves asking for a treatment and seeking a doctor's agreement to provide this treatment.

Where the doctor agrees to provide the treatment suggested by the patient, it is reasonable for the doctor to want to understand the treatment well enough to be satisfied that there can be no unintended harm caused by that treatment.

Patients should ask to have their request documented in their medical records as well as their acceptance of any risk that has been suggested by the doctor.



It is also reasonable for the patient to have refusal by a doctor to provide treatment documented in the medical record with reasons for this refusal.

Where a doctor proposes a treatment that the patient is sure will be unsuccessful, the patient is entitled to refuse the treatment.

Where a doctor proposes a treatment that the patient is sure will be the wrong treatment, the patient is entitled to refuse this treatment. It is important that the patient's reasons for their refusal be fully documented in their medical record.