

UNDERSTANDING is
crucial to making
an informed choice
about your
medical treatment.



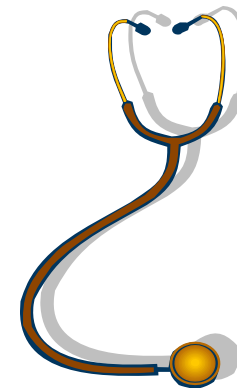
**The Health Consumers' Council
is an independent
community based organisation
representing the consumers'
'voice' in health policy,
planning, research and
service delivery.**

If medical personnel
do not understand
any detail of
your condition
or the treatment,
they should ask
you questions and
seek other information.

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Treatment of rare medical conditions



- In emergencies
- Consent issues

The Health Consumers' Council WA (Inc)

People 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 expert in the signs, symptoms and treatments for their condition, including:

- When to seek treatment
- The urgency of their need
- Treatment that has worked in the past, and
- Treatments that have not worked.

Issues for the patient, where a rare medical condition needs to be treated in an emergency:

- Knowing what you need but not having the power to access this
- Concern about your judgements and views not being trusted or believed
- Fear of the consequences of not being treated.

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

- Not knowing what treatment to offer
- Being asked to trust the patient's judgement
- Concern about their responsibility if something goes wrong.

Consent to treatment for people with a rare medical condition

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

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

Where a doctor agrees to provide the treatment suggested by the patient, it is reasonable for the doctor to want to know enough about the treatment 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 ask to have any 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 the wrong treatment, the patient is entitled to refuse this treatment. It is important for the patient's reasons for their refusal to be documented fully in their medical record.

What patients can do

When they have a rare medical condition and are seeking emergency treatment:

- Approach treating doctors with openness and without defensiveness
- Provide any brief and informative documentation that you may have about your condition
- Provide contact details of your primary specialist, if you have these
- Provide your authority for a carer or friend to speak for you, if appropriate.

What doctors can do

When treating a person with a rare medical condition in an emergency:

- Approach patients with rare conditions with openness and without pre-judgement
- Give credence to information offered, whether verbal or documentary
- Be prepared to contact specialists for advice
- Give regard to any carer or friend who may be assisting your patient, if appropriate.

This pamphlet addresses conditions that have a confirmed diagnosis, not conditions where symptoms are unusual but no diagnosis has yet been reached.