



**Neuroendocrine
Cancer UK**

Incorporating The Ann Edgar Trust



NEUROENDOCRINE CANCER GUIDE

TREATMENT: PREPARATION & CONSENT

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www.neuroendocrinecancer.org.uk



Before you have any treatment, your doctor will explain its aims. They will usually ask you to sign a form saying that you give permission (consent) for the hospital staff to give you the treatment. No medical treatment can be given without your consent.

In this guide we will discuss the different types of consent, and also offer support on how to prepare for any upcoming treatment - physically and mentally and practically. You might need to organise some practical issues such as work, benefits, childcare and pet care.

I was helped by the openness of health professionals, friends and family. Don't be afraid to ask for help, however small it is. People are keen to do something.

Neuroendocrine Cancer patient.



Consent

The dictionary definition of consent is “To give permission for something to happen or agreement to do something”. The principle of consent is an important part of medical ethics and international human rights law. As such, consent should be obtained willingly – that is, without coercion, inducement, undue influence or pressure.

In healthcare it is about your agreement – giving your permission – to receive any type of medical care, including; physical examination, test or treatment.

Before anything happens, you should receive a clear explanation of the reasons for and potential consequences of the examination, test or treatment. Also, time to consider your decision and the opportunity to ask any questions you may have and / or to express any concerns.

You do not have to give your permission, but as consent is needed before anything takes places. If you do not agree to it, it won't happen. And remember that even if you have given consent but change your mind at any point before the examination, test or treatment starts, you are fully entitled to withdraw your earlier consent – and it will stop or not go ahead.

There are different types of consent



Non-verbal

For example, holding your arm out to allow for a blood test to occur



Verbal

For example, saying you are happy to go ahead with a scan



Written

For example, signing a consent form for surgery

However, for each of these it is vitally important that the healthcare professional responsible for undertaking the examination, test or treatment, ensures that you understand what is going to happen – as well as any potential risks or side effects. For example – bleeding from or bruising at the needle site after having blood taken.



Consent must be voluntary and informed, and you must have the capacity to make the decision.

The meaning of these terms are:

Voluntary

The decision to give or withhold consent is yours – and yours alone! It must not be coerced or unduly influenced by pressure from medical staff, friends or family.

Informed

You must be given all of the information about what the examination, test or treatment involves, including the benefits and risks, whether there are reasonable alternatives, and what will happen if it does not go ahead. Informed consent is also about ensuring that you understand the information you have been given, have had time to think about the information and been given the opportunity to ask any questions you may have – and received the answers you need.

Capacity

You must be capable of giving consent, which means that you need to be able to understand the information you have been given and have the ability to use it to make an informed decision.

If you have the capacity to make a voluntary and informed decision to give or withhold your consent – your decision must be respected.

Consent by others

If you do not have the capacity to decide about an examination, test or treatment and you have not appointed a lasting power of attorney (LPA) the healthcare professionals responsible for your care may go ahead - if they believe it's in your best interests.

However, the healthcare professionals involved must take reasonable steps to discuss the situation with your next of kin, friends or relatives before making these decisions.



Consent from children and young people

If they're able to, consent is usually given by the child themselves. However, up to the age of 16, the person with parental responsibility may need to give consent for a child to have treatment.

Making your wishes known

A person may be being kept alive with supportive treatments, such as lung ventilation, if an "Advance Decision" (**Living Will**), which outlines the care they would not like or would refuse to receive, hasn't been made or recorded in their medical records.

In these cases, a decision about continuing or stopping treatment needs to be made based on what that person's best interests are believed to be. To help reach a decision, healthcare professionals should discuss the issue with the relatives and friends of the person receiving the treatment. Making an Advance Decision (Living Will) - or an Advance Statement or a Lasting Powers of Attorney for Health and Welfare - can be completed (and updated) at any time and gives you the opportunity to make your wishes clear, should you, in the future, become unable to confirm those wishes yourself. There are subtle differences between the three.

There are differences between an Advance Decision, an Advance Statement and a Lasting Powers of Attorney for Health and Welfare.

Exceptions to consent

There are a few exceptions when an examination, test or treatment may be able to go ahead without your consent, even if you're capable of giving your permission.





If you believe you have received treatment, on the NHS, that you did not consent to, you can make an official complaint.

If you've made an Advance Decision, Advance Statement or Lasting Power of Attorney, this should be noted in your medical records - and your next of kin/designated representative should be aware of it.

Make sure you make a list of what to pack in your hospital bag eg toiletries, nightwear, underwear, books/magazines, phone charger, snacks, definitely ear plugs. Take a list of all your medications.

Neuroendocrine Cancer patient.

Preparing for treatment

Once you've agreed your treatment with your care team, you will be given a treatment plan explaining what's planned and when. This should cover all aspects of your treatment – including things like; visits to wards or units, as well as aims of treatment alongside risks and benefits. A treatment plan ensures that everyone's expectations are addressed, if you haven't been given a plan – ask if you can have one.

The relationship between you and your health care team should be a partnership, where you work together to:

- Ensure your team understands what is important to you – your preferences of care
- Identify realistic aims of care and / or treatment
- Make decisions about your care and treatment.



Whether you want to know every detail or not, there are a few basics about treatment it's always worth keeping in mind:

- That everyone reacts to treatments differently, which means that comparing yourself to other people may not be helpful, though others may have useful tips that can help you through treatment.
- If you're told treatment may have a certain effect and it doesn't happen, that doesn't necessarily mean the treatment hasn't worked.
- If your cancer can't be cured, the ultimate goal of treatment is often to improve your quality of life – so if you don't feel that's happening, say so.
- If you want to stop treatment – you can. Just let your team know.

Cancer treatments can put a lot of extra strain on your body and preparing yourself physically and psychologically can make it easier to cope with treatment and to recover afterwards.

It is not unusual to feel a bit low in mood, rather than relief, once treatment is completed – usually 1-2 weeks afterwards. This is a perfectly normal reaction and usually improves over time, as you physically recover. Feeling this way, may cause anxiety if you are not aware it may happen. If it occurs, and you are worried about it or it does not seem to get better alongside your physical recovery, you may want to talk with your nurse specialist, clinical team and / or GP.



Help & support is available for you





There may be a number of consequences of having surgery – from how you feel about yourself and your body to physical alterations and changes in ‘normal’ function – depending on the type of surgery and / or other treatments you may have had or need to have to complete treatment.

It can be helpful to discuss these consequences, and what can help to deal with them, before agreeing to going ahead with anything further.

Pre-assessment appointment



Medical History

Being asked a series of questions about your health, medical history, family history and home circumstances. Some questions you may have already answered, so try to think of it as a necessary checklist to ensure your safety and best care – rather than unnecessary repetition.



Tests

Being asked to have a blood test or further examination / investigation – such as an ECG and / or chest x-ray.



Medication

You'll also be given advice about when to take your normal medicines, if you have any.



Any Questions?

An opportunity to ask any further questions you may have about treatment.





E.R.A.S.

ERAS is short for Enhanced Recovery After Surgery. Enhanced recovery is an evidence-based approach that helps people recover more quickly after having major surgery.

Many hospitals throughout the UK – although not all – have enhanced recovery programmes in place, and it's now seen as standard practice following surgery for many procedures.

LEARN MORE



P.R.E.P.A.R.E

PREPARE is a programme based on the principles of the ERAS programme – it was developed primarily for those about to undergo surgery to their oesophagus and / or stomach. The program will provide coaching and tailored support in the areas of:

- physical fitness
- respiratory exercises
- eating well
- psychological wellbeing
- your medication
- smoking and alcohol
- enhanced recovery after your treatment

LEARN MORE



P

Physical
Activity



R

Respiratory
Exercises



E

Eat
Well



P

Psychological
Wellbeing



A

Ask about your
Medication



R

Remove bad
Habits



E

Enhanced
Recovery





Physical Preparation

Physical preparation may include:



Exercising

Certain exercises – from deep breathing exercises to improving core strength (tummy muscles) – although aimed at older adults you may find the advice given on the [NHS website](#) useful.



Making any adjustments to home or social support arrangements

For example, following PRRT couples are recommended to sleep apart for 7-14 days.

- Will you need another bed, or will the sofa be good enough!?
- Do you have home help or other services that may need stopping temporarily or increasing to meet your needs?



Sleep

Try to get enough sleep. Just as exercise and diet play an enormous part in health, so do rest and sleep. If you're struggling to sleep, you can find some helpful information [here](#).



Reviewing Medications

Including discussing preferred pain relief (if this may be needed during and/or after treatment).



Dropping "bad habits"

Such as [stopping smoking](#) or stopping / reducing [alcohol intake](#).



Ensuring other health concerns are addressed

For example; diabetes and / or blood pressure.



Diet & Nutrition

Diet and nutritional advice.





Psychological Preparation

Preparing yourself mentally is important too.
This may include:



Support

Ensuring you have the support you may need – both physically and emotionally. For example, what helps you to deal with stress and worry.



Information

Ensuring you have the information you need – in a way you understand.



Asking questions

and discussing any particular concerns you may have.



Managing Expectations

Being clear on the aim of treatment and how it might make you feel during and after treatment.



Home Support

Think about what kind of help you may need during or after treatment – from shopping to housework to just having someone sit with you for a while.



Mental Health Support

Letting your support team know, you have treatment planned – if you are receiving support from Mental Health Services, (let them know when, where and for how long) – to ensure that they can put in place any added support you may need.



Dependents

If you have others who are dependent on you i.e., parents, children, pets.

- Are arrangements in place for them so that this doesn't become a worry, if help is needed?

