

WORKING WITH YOUR HEALTHCARE TEAM

Being diagnosed with Neuroendocrine Cancer can mean a new or increased involvement in healthcare - with various tests, treatments and appointments taking place.

It is likely that you will see a lot of your healthcare team, not only over the days, weeks and months around your diagnosis, but for many months and years afterwards - indeed, follow up may well continue for the rest of your life.

It may be that you have been or will be referred, at some point, to a Neuroendocrine Cancer Centre of Excellence, or specialist clinic, to be seen by a doctor working within a Neuroendocrine Cancer Multi-disciplinary Team (an MDT). You might only see one or two people from this team when you go to appointments, but they will all be working 'behind the scenes' to create the best outcomes for you.

Some people find talking with medical staff easy, whilst others may find this difficult, especially if the road to diagnosis has been difficult and long - trust may take time to develop. But it is important to be able to talk through your understanding, concerns and questions with your specialist care team - as this will help to be able to work together - so that any and all decisions about your care are fully informed - and your wishes, concerns and choices are known and respected.

Suggestions and tips for working with your specialist care team;

- Ask questions
- Never be afraid to let your nurse/doctor know if they say something or use terms you do not understand -- they may be so familiar with certain terms that it can be easy to forget sometimes that these terms are not used in everyday life
- Use a diary, notepad or phone App, to keep track of appointments, tests, questions, and other bits of information that you may find useful.
- Make sure you have a point of contact - and information of the days/times they may be available and the best way to contact them - is it by phone, email, message service?
- Take a friend or family member with you to consultations - if there is someone you would like to speak or ask questions on your behalf - let your team know who this is - so that they know who in particular you would like involved in your care
- Do let your team know not only about any symptoms you may be experiencing - but also how you are feeling in yourself and about your care
- Do let your team know about any medications, supplements or complementary therapies you may be taking - including any changes. If your treatment plan includes starting a new drug, there may be interactions - these can be avoided if your team knows about anything you may be taking.
- Let them know about any dependents - including pets - that may need care to be arranged should you need to go into hospital or any other circumstances that may affect your decision-making on care.

Personality clashes can happen in all walks of life - even in healthcare. We all find it easier to get along with some people more than others. If this happens - and is affecting the communication between you and the healthcare professional you see, you can ask to see another member of the team

- If you are unhappy about any aspect of your care - ask to speak with a member of the team you trust, to see if you can talk this through.
- If you really can't do this - or if you would like help in doing this - you can contact the PALS team.

PALS is the Patient Advocacy and Liaison Team - and they work within hospitals to help resolve any difficulties - including communicating with your team.