

MARCH 2022

Not Just NE Cancer Series

Treatments



ABOUT NEUROENDOCRINE CANCER UK

VISION

Our vision is of a world in which people know how to recognise, diagnose, treat, care for, and ultimately, cure patients with Neuroendocrine Cancer

MISSION

Our purpose is to support and inform patients and families from diagnosis, enabling access to the best care and treatment, whilst stimulating Neuroendocrine Cancer research, increasing national awareness and influencing improvements in outcomes.

About the 'Not Just NE Cancer Series'

Our focus, message and slogan for 2022 is 'NeuroEndocrine Cancer is not just NE Cancer' and this year NCUK will educate, inform and support its online community by taking viewers on a virtual journey right from symptoms prior to diagnosis through to treatments, follow up, and looking after your emotional wellbeing etc.

Included in the series, our online community will have access to the following:

- Informative, educational and supportive online content
- Real-life patient experience videos
- Monthly podcasts
- Educational videos from the experts
- The opportunity to 'Have your Say' in our monthly survey
- A chance to feature in our Faces & Voices of NCUK campaign.

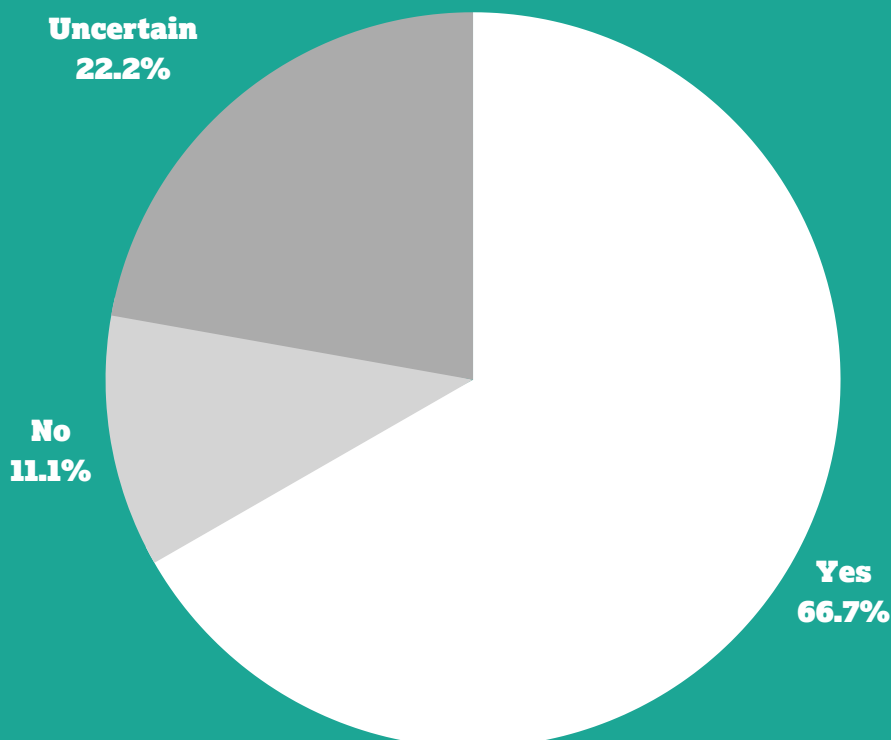
Summary of Results

For this month's survey, we asked our online community about their Neuroendocrine Cancer treatments. We obtained responses from 109 participants from across the whole of the United Kingdom.

Thank you to everyone who completed the survey you have not only provided us with a better understanding of the community's needs, you are also helping drive our future projects and plans. We want to ensure that the work we do, will be most beneficial to all affected by Neuroendocrine Cancer.



Q1. DO YOU FEEL LIKE YOU HAD/HAVE A GOOD RELATIONSHIP WITH THE HEALTH CARE TEAM INVOLVED IN YOUR TREATMENT?

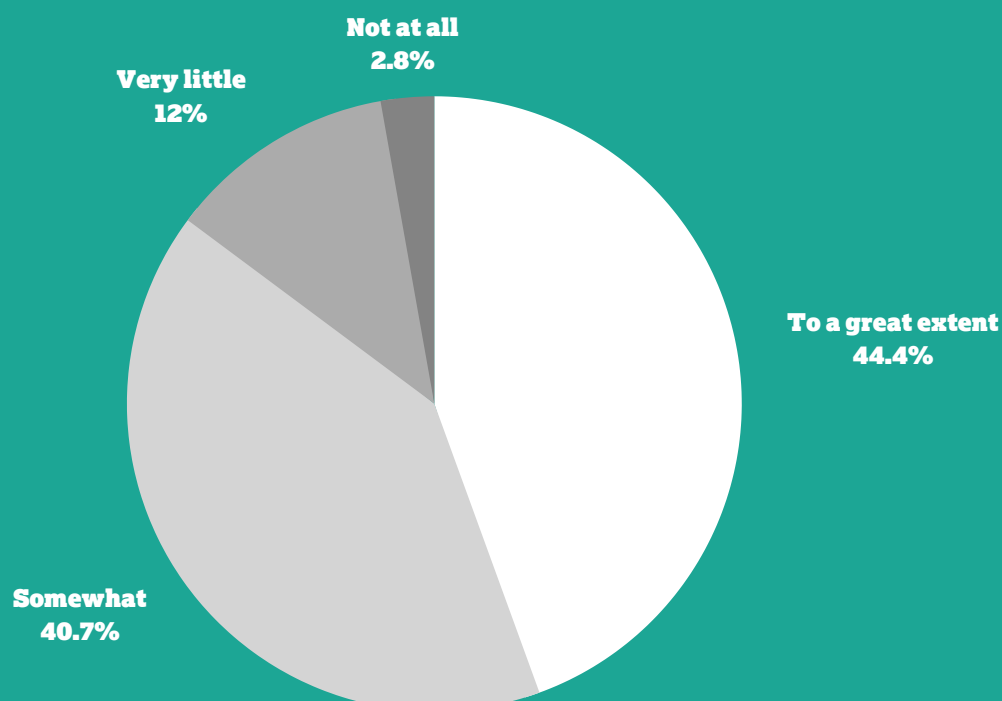




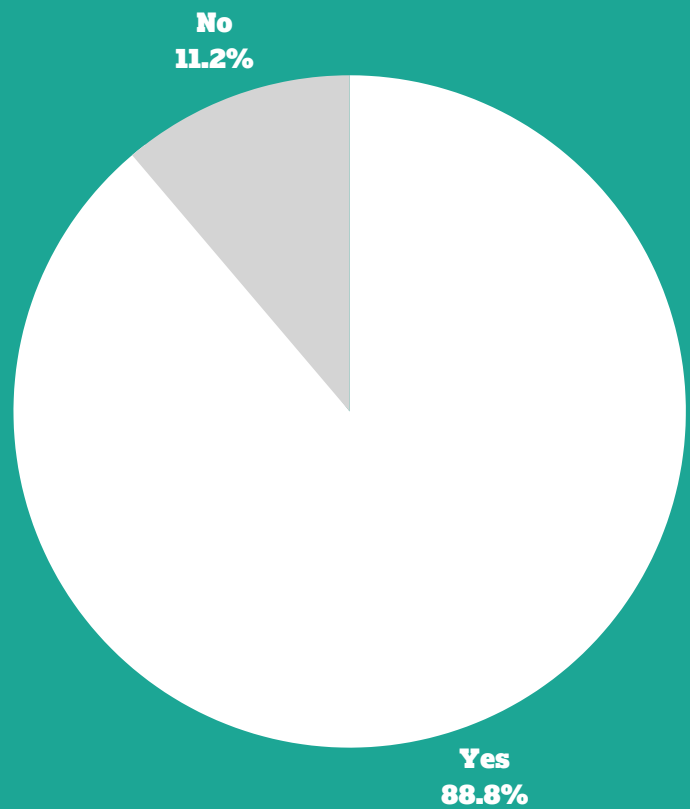
Q2. IF YOU ANSWERED NO OR UNCERTAIN TO QUESTION 1, COULD YOU COMMENT ON WHY YOU FEEL/FELT THIS WAY?

- The team are very busy. I rarely see the same consultant more than twice. If I email/phone with questions can take a week for a reply. When I actually meet the team they are helpful. They are just too busy.
- I don't feel they realise how worrying having had NETs is. Even getting good scan results doesn't stop the worry.
- I've felt that at times I've had to push hard and challenge strongly some of the decisions made about my care as I was not satisfied with the explanations. I've also felt that I had to advocate really hard for more information about my care and about living with the consequences of treatment, in some cases I felt that unless I "exaggerated" my symptoms, I was not taken seriously or action was slow to come.
- Lockdown has been horrific getting phone calls from people I mostly don't know is not helpful.
- Very early into diagnosis and got one story from one doctor and another story from another doctor on the same visit.

Q3. TO WHAT EXTENT DID YOU FEEL YOU WERE INVOLVED IN YOUR TREATMENT DECISIONS?



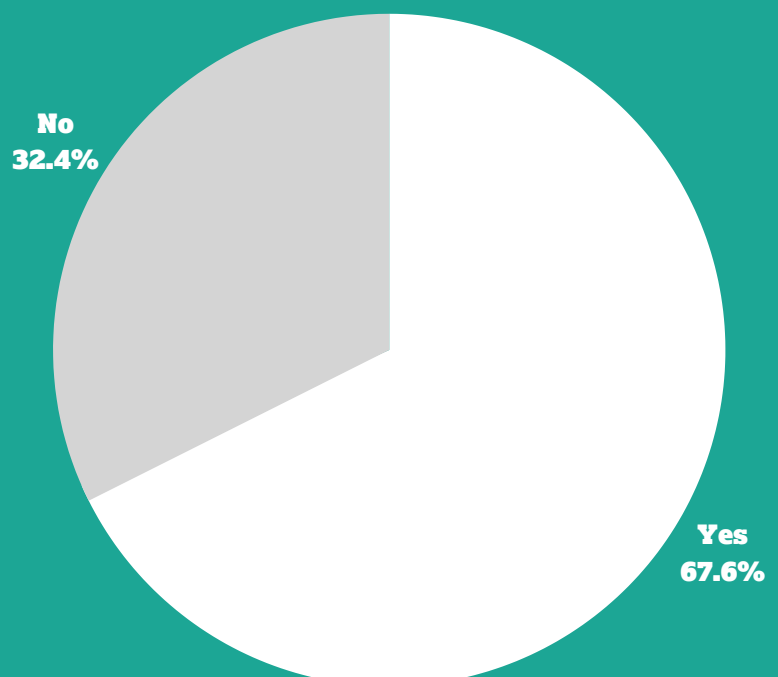
Q4. CONSENT FOR TREATMENT - DID YOU FEEL THAT YOU HAD RECEIVED ENOUGH INFORMATION BEFORE AGREEING TO TREATMENT / SIGNING CONSENT FORM ?



Q5. IF YOU ANSWERED NO TO QUESTION 4 - PLEASE COULD YOU COMMENT ON WHY YOU FEEL/FELT THIS WAY?

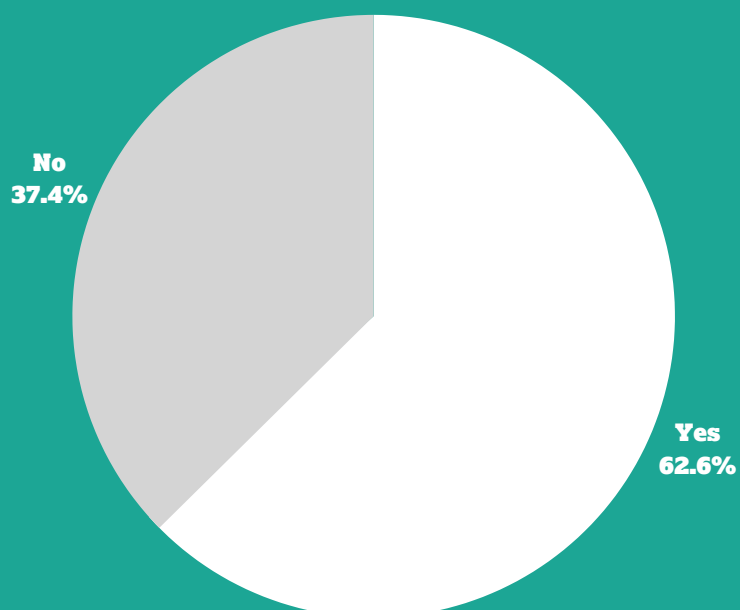
- I have felt that treatment was always explained well, however there was not enough emphasis on explaining the consequences of treatment and what that impact might look like. And whilst I'm grateful to still be alive because of all the treatment I've had, I often wonder whether I'd gone through with some of it if I'd understood the consequences better.
- I didn't really understand what was going on but when you are told it is the only option, you have to trust them and just do it.
- I just wasn't sure of what the treatment would help with and what the possibilities of positive treatment could do so just wasn't aware myself.
- On reflection I wish I had asked more questions.

Q6. WERE YOU GIVEN A TREATMENT PLAN EXPLAINING WHAT WAS PLANNED AND WHEN?

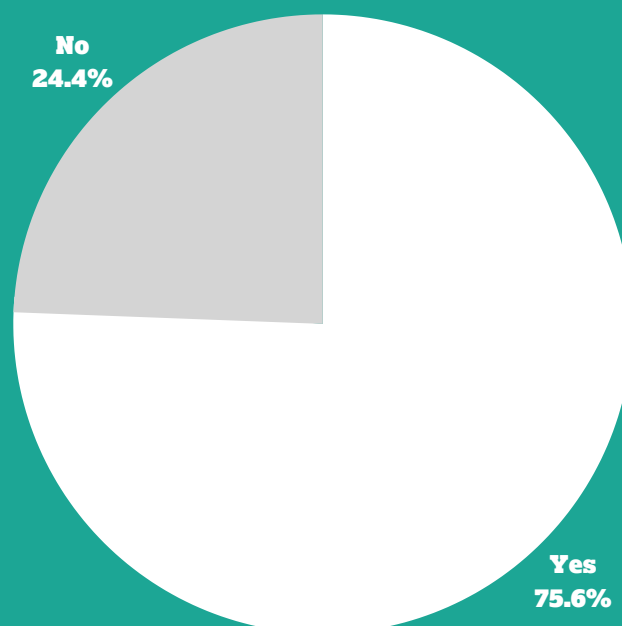




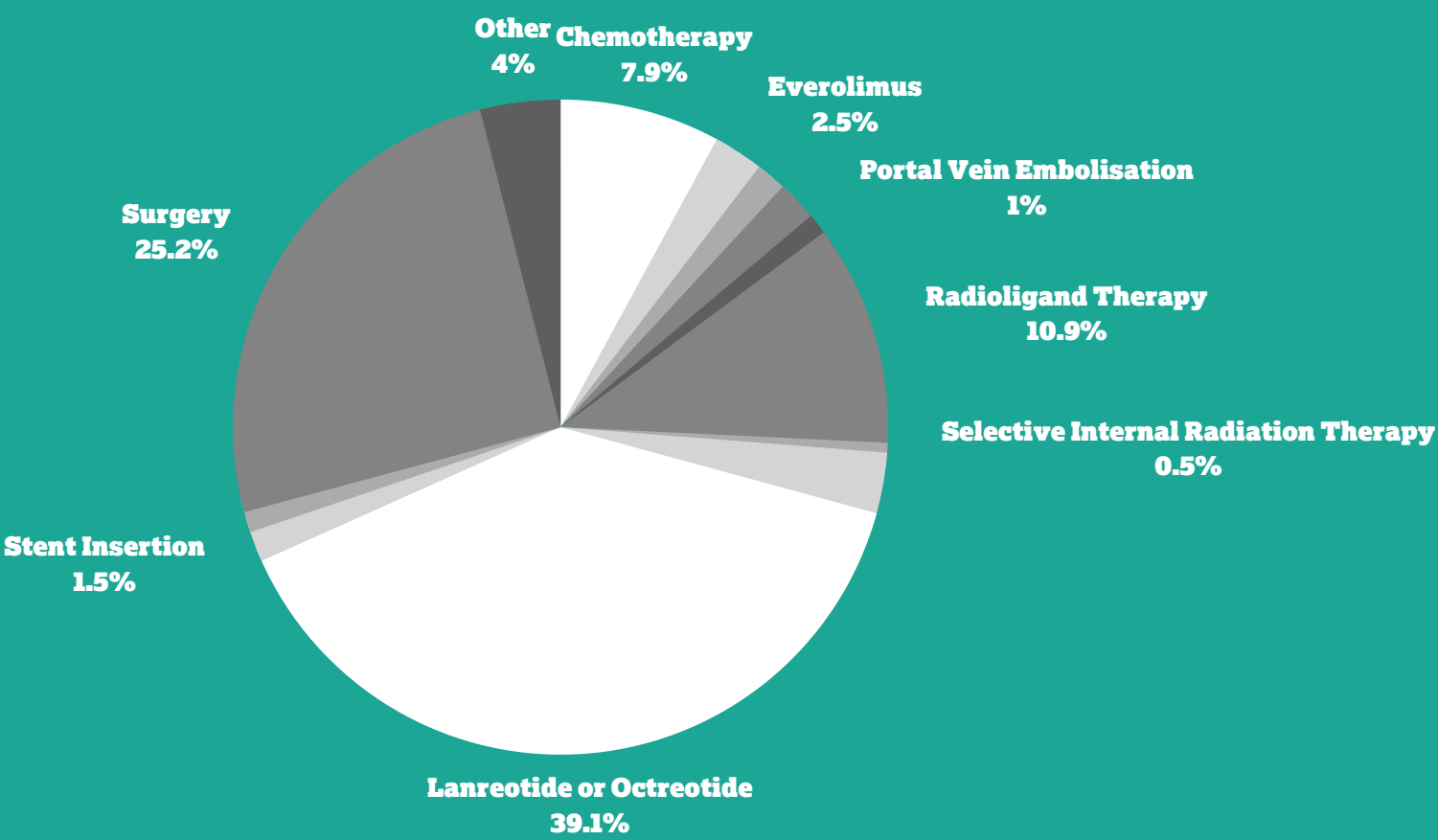
Q7. WERE YOU GIVEN ANY WRITTEN INFORMATION ABOUT YOUR TREATMENT TO TAKE HOME WITH YOU ?



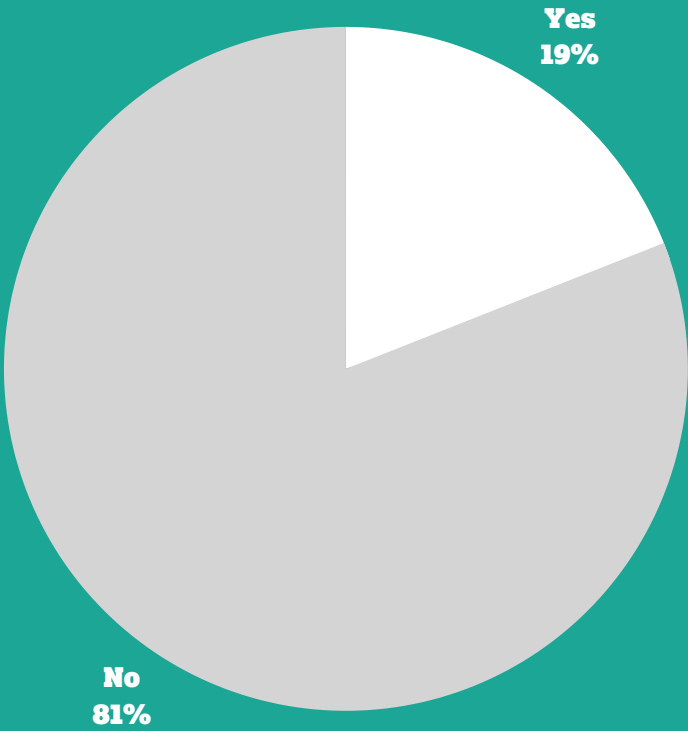
Q8. IF YES TO QUESTION 7, DID THIS INCLUDE INFORMATION ABOUT THE POSSIBLE SIDE EFFECTS / CONSEQUENCES OF TREATMENT ?



Q9. WHICH TREATMENT(S) HAVE YOU RECEIVED FOR YOUR NEUROENDOCRINE CANCER?



Q10 HAVE YOU EVER BEEN OFFERED OR TAKEN PART IN A CLINICAL TRIAL?



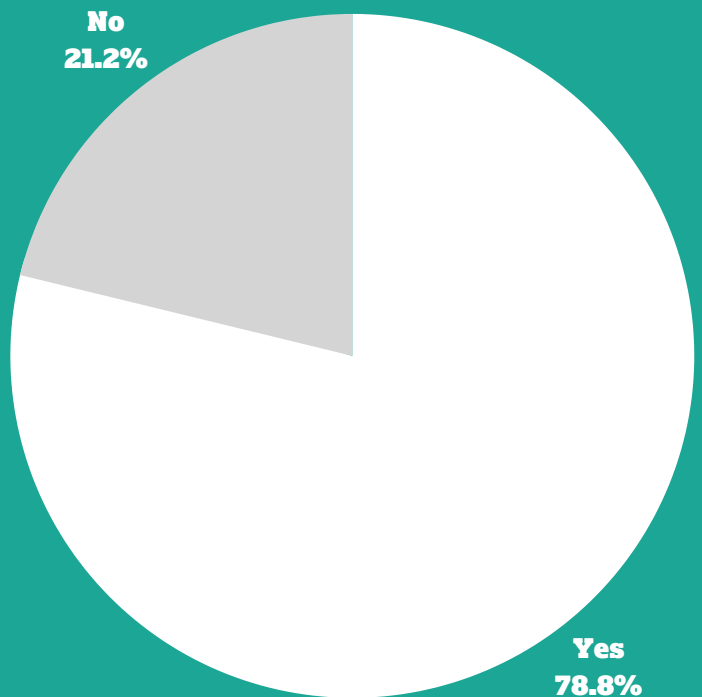


Q11. WHAT, IF ANYTHING, HELPED YOU TO PREPARE FOR HAVING TREATMENT - PHYSICALLY AND EMOTIONALLY ?

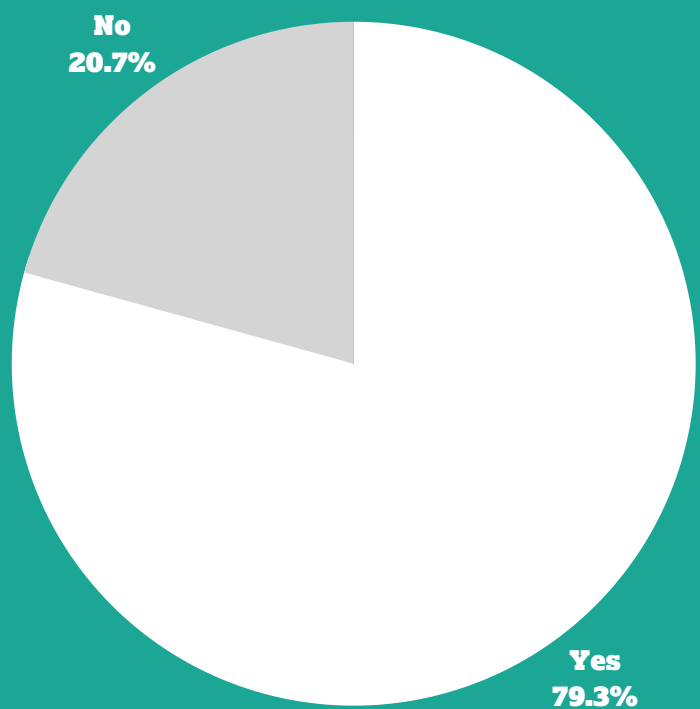
- Getting advice from other NET patients on NCUK Facebook page.
- Meditation and support from nurses.
- Prepared for surgery:- physically, by lots of running and improving fitness and emotionally by talking a lot to lots of people and especially those closest to me.
- Not dwelling on the 'what ifs'.
- Having all arrangements made in advance - hotel, transport, food etc.
- Made a list of what to put into hospital bag.
- Counselling.
- Lots of research and chatting it through with family.
- An in depth explanation of what will happen each month and how it may affect me and to go through options available if i feel it hard to cope.
- I was advised to go walking to get fit before surgery. I believe gentle exercise before and after surgery has helped with my recovery.
- Information about treatment and side effects.
- Creating a comfortable base to rest when it gets tough.



Q12. DID YOU HAVE / ARE YOU EXPERIENCING ANY SIDE-EFFECTS FROM YOUR TREATMENT?



Q14. IF YOU ANSWERED YES TO QUESTION 12 - DID YOU HAVE / DO YOU HAVE A POINT OF CONTACT TO REPORT AND/OR HELP MANAGE YOUR SIDE-EFFECTS?





Q15. WHAT ADVICE WOULD YOU GIVE SOMEONE DUE TO HAVE THEIR TREATMENT AS AN OUTPATIENT OR AT HOME ? WHAT HELPED OR WOULD HAVE HELPED YOU ?

- Take all medications as prescribed, even those that state "as needed".
- Have someone with you when your treatment is explained.
- Have a good contact to prevent panic if reactions do occur!
- Take each day at a time. Rest when you need to.
- Be patient, it takes time for one's body to acclimatise to the new chemicals being introduced into your body.
- Ask them [your care team] about what side effects others experience, and what to do when they do. Who to call, what to anticipate.
- I've found that being taught how to self inject lanreotide meant I am to take at the time of day that is most convenient to me. Usually first thing in the morning. Ensuring that there are plenty of other things to do on treatment days always helps me think the injection is just one thing among many that I've got to do today.
- Talk to the experts, express your concerns. Talk to family members. The power of prayer always helps.
- Make sure you have a specialist nurse to support you. Report all your side effects.
- Drink plenty fluids and make sure you don't become constipated.
- 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.
- Determine the side effects before the treatment.
- Be prepared for good and bad days health feeling wise.
- Having a good dietician's input to help me keep my energies up.
- Stay positive, set goals, plan trips or events, reward yourself as you emerge from each cycle with a special treat.



Q16. WHAT ADVICE WOULD YOU GIVE TO SOMEONE DUE TO HAVE TREATMENT IN HOSPITAL ? WHAT HELPED OR WOULD HAVE HELPED YOU ?

- After surgery you may lose your appetite. You may not be able to tolerate eating hospital food. Ask the nursing staff if there are other options you can have - you'd be surprised what there might be in offer in the ward kitchen!
- Make sure you know what is happening, when and why, and speak to your team as well as other patients who have had the same or similar experience.
- Make sure you have time to rest afterwards and not expect to feel 'normal' for quite a while.
- Wards are very noisy and it is difficult to rest. Bring ear plugs and good face masks and comfortable night wear. Try to get dressed and move about.
- For surgery I thought I'd armed myself with all the information I'd need about what was going to happen and what the recovery period might be only to be confronted by choices about pain relief and convalescence being quicker than advertised. My advice would be don't be surprised to be surprised. Surgery is a major event and you'll likely have a strong emotional response to it. It will seem very unlikely at times but you will recover and feel so much better.
- Breathing exercises to help with tension and stress. More sleep, I was totally exhausted from lack of sleep.
- Talk to the experts, read up on the treatment so you know what to expect. Ask questions to ensure you understand the process. Talk to the staff, if you need help ask for it, don't hesitate
- 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.
- If it is possible to exercise before surgery do so because it helps with recovery.
- Get as much information as possible about what happens in hospital and if possible see the treatment area.
- Find what is involved. Can you wear certain clothing or take anything with you to improve your comfort . I was admitted as an emergency so had little time to prepare but being treated with kindness and honesty helped.