

Living with Neuro-Endocrine Tumour (NET)

A leaflet for people who have been diagnosed with a Neuro-Endocrine Tumour (NET)

This leaflet is for people who have been diagnosed with a Neuro-Endocrine Tumour (NET), who are currently receiving or have received medical treatment. As well as the physical effects of NET, some people find that the experience of this illness can have an emotional impact. This leaflet provides some information about the ways people can be affected, some strategies that may help, and what further support is available. The first part describes some of the common reactions to NET, and how it can affect different parts of your life (not all of these will apply to everyone). From page 7 onwards, it offers some ideas about how to manage some of the difficult thoughts and feelings that can accompany living with NET, and will help you think about how to make choices that may improve your quality of life.



There is a lot of information in this booklet and it may be helpful to read it several times, in small chunks, or with a friend or family member to get the most from it. You might wish to read part of it for now, and then come back to it at a later stage, whenever you feel ready to do so.

What is NET?

NETs occur when there is an abnormal growth in cells of the neuroendocrine system, which eventually leads to formation of a tumour. These tumours can be located anywhere in the body, but are most commonly found in the intestine, pancreas and lung.

The neuroendocrine system consists of nerve and gland cells, which are located in most organs. The system is cleverly designed to produce certain chemicals or hormones, which are released into the bloodstream to help regulate the workings of different parts of the body (for example, the digestive system). NETs can be classified in a number of ways, including where the cancer started (known as the 'primary tumour'). Another important way they are categorized is as:

1) **Functioning tumours (or symptomatic)**, which produce hormones but in excessive quantities, and can cause different symptoms (see below)

Or

2) **Non-functioning tumours (or asymptomatic)**, which produce chemicals but do not produce any syndromes or hormone-related symptoms (see below)

Other ways tumours can be classified are according to how well '**differentiated**' they are (referring to how mature the cells are), according to a **grade** (referring to how fast the cells are growing), and according to **stage** (referring to size and whether it has spread beyond its original site).

NETs can be difficult for health professionals to recognise and can therefore take time to diagnose. This is due partly to its rarity (5 out of 100,000 are diagnosed each year) but also because they often develop slowly over a number of years, which means that many people may not experience symptoms at first. In addition, even symptomatic patients are often misdiagnosed because their symptoms are similar to those of other diseases and conditions (e.g., IBS, colitis and asthma).

What causes a NET and how is it treated?

Similarly to many other forms of cancer, the exact causes of NETs are unknown. However, they are most likely to affect people over the age of 60, and people who have a rare family syndrome (such as Multiple Endocrine Neoplasia or MEN1) have a higher risk of developing them. Also, if one of your parents has had a NET, your risk of developing it increases slightly. However, it is important to remember that they are rare, and so your risk of developing it is still small.

The treatment of NET varies depending on a number of individual circumstances, for example where the tumour is located, how advanced the tumour is, and your overall health. Whenever possible, the main treatment is surgery to remove the tumour completely. If it cannot be removed, treatment is generally aimed at relieving symptoms and improving quality of life. In some cases where the NET is very slow growing and not causing symptoms, you may not need treatment straight away but will be monitored by the doctor with regular check-ups (this is known as 'watchful waiting').

With a diagnosis of NET, there is always a theoretical risk that the cancer could return. This means that you are unlikely to ever be fully 'discharged' from the hospital team, but that you will continue

to be monitored with ongoing follow-up appointments. However, the gaps between your follow-up appointments will become longer, as long as cancer is not detected.

For further information and explanation about what NET is, its causes and the different treatments available, please speak to the doctor or nurse you see in the NET clinic.

The Effects of NET

There are many different physical and emotional effects of NET, which may ebb and flow over time. Every illness, and every person, is different but below are some examples of the different effects you may experience.

Physical effects

NET can be associated with a number of uncomfortable and unpleasant symptoms, the frequency and intensity of which will vary from person to person. There are two main categories of symptoms; those caused by the tumour itself, and those caused by the hormones it releases.

- Tumour-related symptoms vary according to the location of the tumour, for example, a tumour in the digestive system may cause diarrhoea, nausea, constipation or tummy pains, whilst a tumour in the lung may cause wheezing or a persistent cough.
- Hormone-related symptoms vary according to the gland that is affected by the tumour, and can include diarrhoea, flushing, cramps, wheezing, low blood sugar (hypoglycaemia), changes in blood pressure and heart problems.
- Some NETs may overproduce a particular hormone called serotonin. This substance causes a specific set of symptoms known as carcinoid syndrome. The symptoms of this include diarrhoea, flushing of the skin, wheezing, loss of appetite and weight loss.
- Some of the treatments for NET involve having regular injections, which can cause pain and discomfort. You may also experience unpleasant side effects of other medications.
- If you have had surgery as part of your treatment, you may have had to cope with pain and discomfort following this.
- We know from a recent global survey that 40% of NET patients experience general fatigue, muscle fatigue and weakness on a daily basis.

Emotional effects

It is now commonly recognised that living with NET can have a significant negative impact on your emotional health. There are a number of points along your journey with NET when you may experience difficult emotions. Some of these may include:

- **Before diagnosis** - You may go through many visits to doctors, tests and investigations before you receive a diagnosis, and this time of waiting to discover why you are unwell can be extremely stressful for you and for others close to you.
- **Receiving a diagnosis of NET** - For some of you, this may mean a sense of relief that the symptoms are finally being explained and recognised (for example, it might be the first time someone has confirmed your symptoms are real, and not in your head). However, it is also common to feel a mixture of emotions at this time including confusion, worry, feeling over-whelmed, out of control, or simply numb with shock.
- **Starting a new treatment** - This can also be a difficult time since it may involve several changes and unknowns as you begin new routines, and new medications.
- **Continuing treatment** - While treatment can be a positive experience as your health improves, it can also be demanding, and if it is not straightforward, you may find it hard to cope with the symptoms and endless visits to doctors and clinics.
- **Undergoing an operation** - This can be anxiety-provoking since it may involve disruption to your

day to day routine, numerous trips to hospital, and concerns about the outcome and your recovery. Recovery from an operation can also be long, tedious and stressful.

- **Living day to day with NET** - Since in many cases, living with NET can mean long periods of 'watchful waiting' or monitoring, this can evoke feelings of helplessness due to the uncertainty of what is to come in the future. You may have regular follow-ups with your doctors, with even more tests and medications, and more treatments to try. Or you may be largely managing your condition on your own, with little contact with medical professionals, which can feel isolating. In addition, other people may think you look physically well, which may make it harder for them to fully understand what you are going through.

Naming the feeling

If you are unsure what you are feeling, talking to someone else is almost always helpful to make sense of it. Once you have noticed and named the feeling, you could ask yourself what triggered the feeling. Was it a thought (such as those mentioned above), a memory or an image? It may also have been something someone said or a physical sensation. Once you have understood the triggers, it can be easier to understand and manage your feelings. It might be helpful to keep a diary of the strong feelings, and to write down the feeling and what triggered it.

Below we have described some of the common difficult feelings you may experience whilst living with NET:

Anger and irritability: You may feel angry about having this condition, about the length of time it has taken to be diagnosed, and about the limitations it puts on your daily life. Some research has also found that carcinoid syndrome may be associated with personality changes, such as being more impulsive, or aggressive.

Low mood or depression: Living with a chronic health condition can increase the likelihood of experiencing low mood or depression. This can mean experiencing a variety of symptoms such as feeling sad or numb, hopeless about the future, having negative thoughts about yourself, other people or the world, feeling lonely, or as though you are carrying the burden of the disease without support. It is important to note that many of the physical symptoms of depression overlap with physical symptoms resulting from the diagnosis or the subsequent treatment of NET, which can make it more difficult to diagnose depression.

If you think you are experiencing depression and have had thoughts that your life is not worth living, it is important to tell a healthcare professional, visit your GP or attend A&E, particularly if you think you might act on these thoughts.

Worry and anxiety: You may be scared, worried or frightened about what the condition means for your future, since this is likely to be uncertain. Many patients find their mind constantly circling with questions such as 'what does this mean for my future?' and 'what will happen next?', which can be difficult to get definitive answers for. You may also have more specific and understandable worries about what impact your condition will have on your work life, financial situation, family life and close relationships. All of these feelings are very normal and it is natural to experience some or all of these feelings at different stages of illness as you continue to process new information and adapt to being a NET patient. It is possible that they will come and go over time and that many will go away by themselves as you begin to come to terms with your condition. However, if they persist then there are a number of different things you can try which may help.

The effect of NET on your thinking

The way we make sense of our experiences depends a lot on how we think about them. We can have positive 'glass half full' thoughts which may be really helpful and allow us to get through difficult times. However, often in times of stress, our minds come up with scare stories instead, which can be less helpful. Often there is a noticeable pattern to these negative thoughts which are known as 'unhelpful thinking styles'. Everyone can fall into these patterns at times, and they are often so automatic, that they happen beyond our awareness. Sometimes just being able to notice and recognise these thinking patterns can be useful. Some examples of such thinking styles are set out below:

Thinking Style	Examples commonly associated with feeling anxious or worried
Thinking the worst	"This diagnosis will mean I will lose my job and my family won't be able to cope"
Predicting the future	"What if I have to take time off work and lose all respect from my colleagues?"

Thinking Style	Examples commonly associated with feeling low or depressed
Self-criticism and labelling	"I cannot seem to snap out of this low mood and stay positive. I am a failure"
Pressurising language: (shoulds, oughts, musts)	"I should be able to cope with this and I ought to be able to continue living a normal life. I must get on top of this"
Black and white thinking	"Nothing is improving, I may as well give up"

Thinking Style	Examples commonly associated with feeling angry
Mind-reading	"The doctors think I am stupid."
Black and white thinking	"The doctors always let me down" "That was a complete waste of time"

You might identify with some or all of these, or be able to think of your own individual examples.

The effect of NET on your behaviour

Some things you do will have a positive effect on how you feel physically and emotionally when you are living with NET, including maintaining a good diet, exercising, maintaining a consistent sleep routine and making time for activities you enjoy such as hobbies and socialising. Other things like smoking, using drugs, drinking too much alcohol, or spending a lot of time playing video games or watching TV can seem to offer immediate relief, but make you feel worse in the long-term.

If you are experiencing an 'emotional rollercoaster' whilst living with NET, you may notice some of the strong feelings try to convince you that you should not do things while you feel this way and that you should wait for the strong feelings to subside. However, waiting for this to happen can put life on hold and make you feel stuck. It is important to notice your feelings, but not let them entirely dictate what you should or should not do.

You may find that you start avoiding things because of feeling anxious, low or because of physical discomfort, for example you may put off seeing your medical team or stop doing things you used to

enjoy. This can make life seem easier in the short term because you do not have to face the situation you fear, overcome the feeling that you 'can't be bothered' or tolerate the unpleasant physical symptoms. However, this can be unhelpful in the long term and lead you to feeling stuck. For example, putting off your hospital visit due to fear can lead to more anxiety because you never find out if your fears come true. Similarly, cancelling plans with friends because you feel low can make things worse because you do not get the chance to experience fun, pleasure and a sense of achievement.

Vicious and Virtuous Cycles

The sections above describe the ways that your body, thoughts, feelings and behaviours can be affected by NET. You may have noticed how these things are all closely linked, which means a change in one area can have a knock-on effect in another area. For example, the thoughts we have about a situation can affect how we feel physically and emotionally, as well as what we choose to do. This relationship can be understood in the form of a cycle and whilst some cycles can interact in positive and helpful ways ('virtuous cycles'), others can interact in negative and unhelpful ways ('vicious cycles').

Below is one example of a vicious cycle (in text and diagram form):

Joe was finding the NET treatment draining and didn't have much energy so he decided to stay at home. He soon felt bored which led to feeling grumpy, lethargic and increasingly hopeless. After a few weeks, when he did try and go out and do something, he got exhausted really quickly and thought to himself "if I feel this tired it means I was right to stay at home and rest. If I can't do this, what hope is there for the future?". This meant that he did not go out again and felt more lonely and depressed.

PHYSICAL SYMPTOMS (How we feel physically)

E.g., Joe experienced extreme tiredness and lethargy

THOUGHTS (How we think)

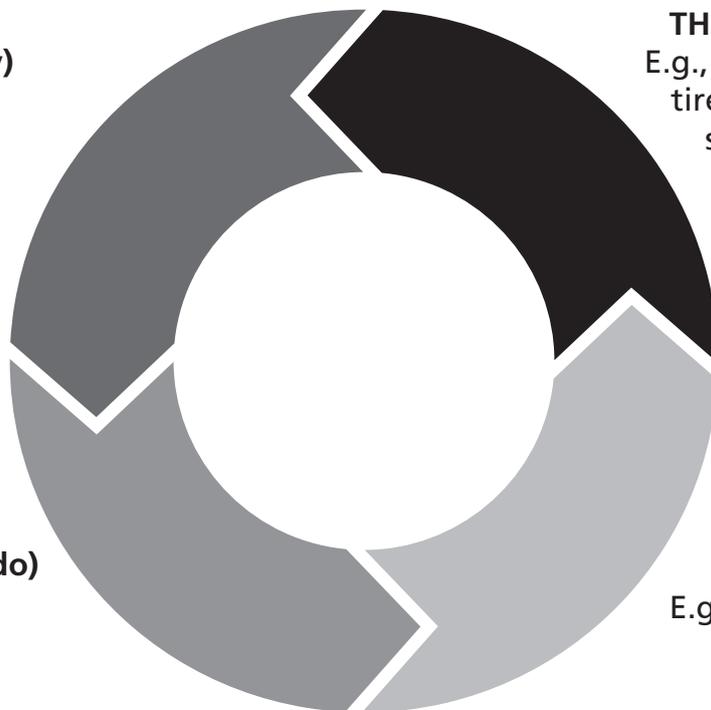
E.g., Joe thought 'if I feel this tired it means I was right to stay at home and rest. If I can't do this, what hope is there for the future?' and 'I will become very lonely'

BEHAVIOUR (What we do)

E.g., Joe avoided going out altogether

FEELINGS (How we feel emotionally)

E.g., Joe felt bored, grumpy and hopeless



Coping with NET

There are a number of different strategies you could try using to turn the 'vicious' cycle into a 'virtuous' one, and these can be divided into either trying to tackle the unhelpful thoughts, or trying to tackle the unhelpful behaviours.

Tackling unhelpful thoughts

Thoughts enter our minds constantly throughout the day, and can be pleasant, unpleasant or neutral. You could think of the mind as like a storyteller or narrator which is constantly commenting on what is happening around us. Often the mind comments in helpful ways, drawing our attention to interesting or pleasant things, reminding us of happy memories from the past or alerting us to things we have planned in the future. However, sometimes during times of stress, the mind can be less helpful and instead, might draw our attention to unpleasant things, remind us of negative memories from the past or make scary predictions about the future. Although it can seem as though these thoughts represent reality and are 100% truthful, this is not always the case. It can be hard to remember that thoughts are just thoughts, and not facts, which is why we can get into difficulties.

The first step in tackling unhelpful thoughts is to notice what they are, perhaps by trying to pay attention to what your mind is saying (or 'narrating').

The next step is to step back from your thoughts and question them, since they are often based on the wrong assumptions. You could ask yourself the following questions:

- What makes me think this thought is true?
- Is there anything to suggest this thought may not be true?
- Is there another way of looking at this?
- Based on the evidence for and against this thought being true, what is the most logical or balanced alternative perspective?
- If a friend who I cared deeply about had this thought about themselves or their situation, what would I say to them?
- What are the costs and benefits of thinking this way?

While challenging thoughts in this way may not stop them coming into your mind, it could help you feel less upset or distressed by them.

Here is an example of how this method could be applied to Joe's situation:

Joe didn't have any energy so he decided to stay at home. He soon felt bored which lead to feeling grumpy, low in mood and lethargic. After a few weeks, when he did try and go out and do something, he got exhausted really quickly and he initially thought to himself "if I feel this tired it means I was right to stay at home and rest. I'm not up to this". However, he was able to notice that this was an unhelpful thought and so decided to question how true it was. He asked himself what he would say to a friend in this situation and thought he might say "just because you are feeling a bit tired, this does not mean you should give up on going out as this might make you feel even worse. It is natural to feel tired but you have made the first important step. Perhaps you should try and go out again tomorrow for a short time and gradually build up your strength". This helped Joe to construct an alternative, more balanced and helpful thought, which lead to a plan to try a different behaviour (going out for a shorter walk). Gradually he began to go out more and more and he slowly noticed his energy levels improve, which helped him feel less hopeless and low.

Using a mindful approach

If the above strategy does not work for you, or you are finding it hard to name your thoughts, another method you could try is to apply a mindful approach. This is a way of becoming more aware of our mind and body right now, and can help us detect certain feelings, unhelpful thoughts or images. Often we can get caught up in reacting to thoughts or feelings automatically, without a successful outcome. Instead, mindfulness encourages us to take a curious stance towards our experiences, including thoughts, feelings and sensations. It teaches us to simply notice them without judgement or trying to change them. To start with, you could try following these simple steps:

First notice the thought that has popped into your mind

Try not to judge the thought as good or bad, just notice it

You could thank your mind, the storyteller, for its contribution to your day

Then ask yourself, is this thought a helpful one? If so, then perhaps pay attention to it and act on it

If it is not helpful, and your experience tells you that these thoughts make you feel bad and keep you stuck, just observe the thought instead of reacting or responding

You could try seeing the thought in your mind's eye being a headline on a newspaper that tends to print exaggerated stories

Then let the thought drift away, like leaves on a stream, or cars passing by outside your window

Being mindful of your experiences is a very different way to our natural way of paying attention and can take practise. There are many good books, CDs and apps for mindfulness if you think this approach might be helpful for you.

You can also find some mindfulness recordings at:

<http://www.kcl.ac.uk/ioppn/depts/pm/research/imparts/Self-help-materials.aspx>

Tackling unhelpful behaviours

Sometimes it can feel too difficult to notice and challenge our thoughts and you may find it easier to work on tackling unhelpful behaviours to start with instead. You may have received lots of advice about eating a balanced diet, establishing a good sleep pattern, exercising regularly, avoiding drugs and alcohol, and taking medications as prescribed. Often it can be easier to start doing new, more helpful behaviours, than to try and stop doing unhelpful ones.

To do this, try to ask yourself what is important to you and what your values are (e.g., family, friendships, your health, your work or your hobbies). Then try to do something most days that keeps you moving in the direction of what matters to you most. You may need to try out new approaches if your old strategies don't work.

Do things you enjoy and that bring you fun, pleasure and laughter. This could mean meeting a friend who makes you laugh, watching a repeat of a comedy show or making time for things you relish such as watching sport or soaking in the bath. Also, try to do things that give you a sense of mastery or achievement.

If you want to make a change, such as taking steps to quit smoking or lose weight, try to set a specific goal (use the **SMART** rule which stands for **S**pecific, **M**easurable, **A**chievable, **R**ealistic and **T**ime-limited), write it down and reward yourself once you have achieved it. If you have a setback, do not give yourself a hard time but remind yourself that setbacks are normal and remain curious about what went wrong so you can think about what do differently next time. If you think it was unrealistic, reset your goal and re-commit to it, rather than giving up. If you have several barriers which you struggle to overcome, try using a 'problem-solving' approach (see **IMPARTS** leaflet, '*Problem Solving for People Living with Health Conditions*').

Dealing with anger

We all feel angry at times but it can become a problem if it is too extreme, occurs at inappropriate times or lasts too long. The feeling of anger exists on a continuum, from a simple irritation with something to intense fury and rage. We often feel angry when we feel let down in some way, or denied of something that we feel entitled towards. The feeling of anger can also mean behaving in certain ways, for example shouting, becoming violent or running away. These angry behaviours can have a negative impact on our relationships and our work, and can change the way we feel about ourselves.

As with all emotion, the experience of anger is accompanied by a number of strong physical sensations in the body. This is due to our body's instinctive and automatic 'fight or flight' response to a threat, which means adrenalin is released to energise the body to either confront the danger, or run away from it. Some of the physical sensations you may notice include heart racing or pounding (enabling good blood supply around the body), breathing quickly (allowing more oxygen around the body), tense muscles (in a state of readiness to fight or flee), shaking, sweating, light-headed, stomach churning or butterflies, fist or teeth clenching.

In the context of living with NET, you may feel angry about the treatment you have received, about the way things have been communicated, or about how others are reacting towards your situation. You may also find yourself feeling angry about what has happened to you. Sometimes anger is directed at the illness, and sometimes people report feeling anger towards the healthcare team or the hospital. However, there are ways you can learn to deal with anger, by applying some of the techniques already discussed.

• **Challenging angry thoughts**

- Try to recognise the content of your angry thoughts e.g., 'I cannot tolerate inefficiency' or 'no one else is helping me'.
- Try using some of the questions outlined above to challenge your unhelpful thought e.g., 'how important is this really?' or 'what are the costs and benefits of thinking this way?'
- You can then try to come up with a more balanced or rational view e.g., 'although it feels as though no one is helping me, several members of my family have offered me support and most of the nurses I have met have seemed friendly and competent. Perhaps I can tell them how I feel and ask them for other sources of support.'

• **Learning new ways to respond**

- Use a relaxation technique such as mindful or calming breathing which can help you to slow down your breathing and reduce the intensity of the immediate physical sensations. For example; sit in a comfortable position, then work out a stable breathing rhythm such as breathing in for 2 seconds, and out for 3 seconds. It can be helpful to count as you do this. You may need to practise this several times when not feeling angry, so that it becomes easy to start when you do feel anger building.
- If you can, excuse yourself from the situation in which you feel anger rising and leave to go into a different space or room, then return once you feel calmer.

- Channel your body's energy into a different activity, such as a walk, run or cycle, or maybe some gardening or housework, until you notice the symptoms becoming less intense.
- Try to take a 'time out' or a pause and ask yourself 'what would be the consequences of responding angrily?', 'is there another way of dealing with this?' or 'what would be the most helpful and effective action to take for me, the situation or for the other person?'
- You could try visualising yourself dealing with the situation in a calm, non-aggressive but assertive way.
- Use calming self-statements such as 'calm down', 'take a deep breath' and 'there is no point in getting angry'.

- **Managing stress**

- Identify triggers for your anger and avoid them where you can e.g., rushing to work, traffic jams, shopping during busy periods, or perhaps times of day when you are likely to get angrier, such as at night.
- Build relaxation into your daily routine so that you make time to relax every day. This could be doing something you enjoy, or just being by yourself. Some examples might be reading a book, having a bath, doing something creative, or visiting a friend.
- You could also try practising mindfulness meditation every day, for example the exercise outlined above, or listening to an audio guide.

Dealing with low mood

Feeling low in mood or depressed is common when you have been unwell, particularly if your illness has kept you away from things you usually enjoy.

When you are depressed, you may believe that you are helpless and alone in the world; you often blame yourself for all the shortcomings that you think you have. At the bottom of this, you feel negative about yourself, about the world and about the future, which means you tend to lose interest in what is going on around you and do not get any satisfaction out of the things you used to enjoy. It can become harder to make decisions or carry out simple tasks as you did before. You also may not be sleeping or eating well. Fortunately, once again there are a number of things you can try out which have been shown to help people when they feel depressed.

- **Challenging gloomy thoughts**

- Similar to the other first stages in the sections above, it can be helpful to recognise the unhelpful thoughts you are having about yourself, others or the world e.g., 'I am useless', 'no one is caring' or 'the world is a horrible place'. Everyone has these thoughts from time to time, but for people who are depressed, they tend to be around a lot more of the time.
- Try to remember that these thoughts are automatic and are often not rooted in any logic or reason. They therefore serve no purpose other than to make you feel bad since they are unreasonable and unrealistic.
- When people are depressed they can become trapped in patterns of distorted thinking such as over-generalising, mind-reading, black-and-white thinking or discounting the positive. Ask yourself whether any of these are around for you.
- You could try writing down your negative automatic thoughts and opposite each one, write a more balanced, positive thought, for example:

Negative automatic thought	Balanced thought
"Living with this illness means I can no longer enjoy life".	"Although I have less energy than before, there are still lots of things I can enjoy and get a sense of pleasure and achievement from".

- Often people who are depressed tend to forget important details and think in more general statements such as, 'I have never been good at anything'. Try and train yourself to remember specific details so that good times and experiences are easier to recall. A daily diary can help with this, or you could list past achievements or memories of pleasant experiences.

- **Changing what you do**

- Research tells us that increasing activity can be helpful for overcoming depression. This could mean making a list of things to do, mixing with other people, joining in activities, taking exercise, or simply doing anything you enjoy.
- Make a plan or a schedule of your activities for the week, starting by filling in the things you have to do, such as work, making appointments, doing housework or preparing meals, and then plan other activities in the time you have free.
- Try to find a balance between activities of pleasure (e.g., seeing a friend, having a bath, reading, watching a film), and those of mastery or achievement (e.g., exercise, shopping, decorating, gardening, paying bills, writing a journal). With regards to exercise, you may find it easier to build this up gradually, starting with small steps, especially following an operation, as muscles take time to heal up. Also, with tasks you have been putting off, try breaking them down into smaller stages and tackling them one by one.
- Take care of yourself physically, this means paying attention to your sleeping and eating patterns. If your mind is busy, it could be having an impact on your sleep. You could try some sleep hygiene techniques (see section below).
- Unhelpful coping behaviours can include drinking alcohol, taking drugs or drinking caffeine. Try to avoid doing any of these if you can (speak to someone if you have a problem giving up).
- Think about what really matters to you, i.e., your values. Try to do something most days that keeps you moving in the direction of these values.

Dealing with worry and anxiety

We all experience anxiety from time to time, since it is a normal response to situations that we see as threatening. A certain level of anxiety can even be helpful, for example if we want to perform well or cope with an emergency. As a result of having a chronic illness, it is natural to feel anxious about your recovery, your future health, work, family life or maybe other things. However, it can become a problem if it stays around for a long time since it can make physical symptoms worse, or stop you doing things you usually would enjoy.

The physical sensations associated with anxiety are very similar to those of anger, since it is also a result of the body's instinctive 'fight or flight' response. These symptoms include a racing heart, increased breathing rate, a dry mouth, sweating, tingling and feeling dizzy. The list of tips below could help you to cope with both the thoughts accompanying your anxiety, and with the physical sensations. Remember that anxiety itself is not dangerous or harmful, it is just a feeling.

- **Coping with anxious thoughts**

- Again, the first step towards tackling unhelpful anxious thoughts is to recognise what these are. You might want to keep a diary of the times you are feeling anxious and what types of thoughts are running through your mind (these can be difficult to pinpoint since they are often very fleeting and automatic).
- If it is a realistic worry or problem that is causing you anxiety, try to problem solve it by defining what the problem is (or what the main problem is first), then ask yourself if it is something you can control, or not. If it is something you can control, you may want to try brainstorming as many possible solutions to the problem, then choose one and make a plan of how you will carry this out (see

IMPARTS leaflet, *'Problem Solving for People Living with Health Conditions'* for more detail).

- If the worry is about something you cannot control, you might wish to try using mindfulness (see section above) to help you to tolerate the anxiety, and let it fade away, or you could use some of the tips outlined in the next section below.
- If the worry is in relation to your illness, it might be something you want to get checked out straight away (e.g., a change in your bodily symptoms), or make a note of to ask at your next appointment (see the 'asking for help' section below).
- If your anxious thought is about what your physical symptoms mean (e.g., 'I am dizzy which means I will faint'), try to ask yourself whether this thought is realistic, and come up with a more balanced thought (e.g., 'I have felt dizzy many times before and not fainted. When I fainted, it felt different'). This may take some practise but it will get easier with time!
- Be kind to yourself and try not to block out the worries but accept they are present. Do not criticise yourself for having these worries but try to be kinder to yourself. You could ask yourself 'what would I say to someone who I cared deeply about who was going through this?'

- **Do something different**

- Try to be mindful of unhelpful behaviours that you might be doing to cope with anxiety, for example; avoiding others or activities, or drinking excessive amounts of alcohol, or using drugs. If you are avoiding certain things because of anxiety, try to tackle these fears, which are stopping you, in a graded way.
- If you are afraid of a certain situation, try to stay in that situation and wait for the anxiety to subside. It usually will come down after a few minutes.
- In order to reduce physical symptoms of tension or anxiety, you might want to try relaxation techniques such as controlled breathing, or mindfulness. Some people can relax using other methods such as exercise, listening to music or reading a book, or you might want to find a relaxation or yoga class to try (ask your nurse or doctor for recommendations or search online).
- Distraction can also help you take your mind off your symptoms, or keep your mind occupied whilst your anxiety symptoms begin to fade (you will need to distract yourself for at least 3 minutes before this happens). Try focussing on things around you, study your surroundings in detail or listen to other people's conversations. This can help re-focus your mind off your worries. You could also try doing another activity which you find pleasurable or masterful, in order to distract yourself from worrying.

Dealing with fatigue and sleeping problems

NET patients commonly feel fatigue and/or exhaustion. This could be because of the NET itself, the symptoms caused by NET or a side effect of treatment. The tiredness felt by cancer patients is different from the usual kind of tiredness, since it is often not relieved by rest and sleep. This can make you feel frustrated and overwhelmed and can contribute to low mood since you may feel forced to cancel social engagements, be unable to carry out everyday chores, have difficulty concentrating, or to think clearly, and feel devoid of energy or more emotional than usual.

Below we have listed some things you can try to help you deal with fatigue. For more information about fatigue, its effects and how to cope, please speak to a member of your health team, or read the *'Coping with Fatigue'* leaflet from **MacMillan**.

- Although it might feel counter-intuitive to try exercising when you are tired, we know that engaging in light to moderate exercise every day helps people to feel better and can give them more energy (always talk to your nurse or doctors before you start). You could start with some regular light exercise such as walking, and simple strengthening exercises like standing up and sitting down, and then gradually build up the amount or intensity you do. Exercises that involve gentle movement, stretching

and balance (such as yoga and tai chi) are particularly good. If exercise is impossible, try to stay active in your daily routine. Remember to listen to your body, focus on each day at a time and do not exercise if you feel unwell, are in pain or have any symptoms that worry you.

- It is also important to try and get a good balance between being active, exercising and resting. If you are very tired, it is important to set yourself some rest times throughout the day. You don't have to sleep during these times but just sitting or lying down will help.
- Make things easier for yourself in your day to day routine; whether this is planning your day around your treatment, asking others to help out with daily chores such as cooking or cleaning, doing a little bit of housework each day (rather than a lot in one go), sitting down to do chores such as preparing meals or cleaning, or wearing clothes that are easy to put on and take off.
- You may also want to think about making some adjustments to your working life, for example, this might mean speaking to your employer or HR department and reducing your hours or having some time off.
- Be aware of being tempted into over-exerting yourself when feeling better, which could leave you feeling exhausted the next day. You can break this 'boom and bust' cycle by trying to do a similar amount of activity each day, regardless of how tired you feel. This means doing a bit less than usual on a good day and a bit more than usual on a bad day. Over time, this builds up your fitness and helps to combat fatigue.

If your sleep is being affected by the symptoms of NET, or negative or anxious thoughts associated with it, here are some suggestions you could try to help you sleep better (also see **IMPARTS** leaflet, '*Overcoming Sleep Problems*', for more detailed information):

- **Do not go to bed unless you are sleepy.**

If you are not sleepy at bedtime, then do something else. Read a book, listen to soft music or browse through a magazine. Find something relaxing, but not stimulating, to take your mind off of worries about sleep. This will relax your body and distract your mind.

- **If you are not asleep after 20 minutes, then get out of the bed.**

Find something else to do that will make you feel relaxed. If you can, do this in another room. Your bedroom should be where you go to sleep. It is not a place to go when you are bored. Once you feel sleepy again, go back to bed.

- **Begin rituals that help you relax each night before bed.**

This can include such things as a warm bath, light snack or a few minutes of reading.

- **Try to get up at the same time every morning.**

This can be difficult, but a consistent waking time, even on weekends and holidays, can be really helpful.

- **Get a full night's sleep on a regular basis.**

Get enough sleep so that you feel well-rested nearly every day.

- **Avoid taking naps if you can.**

If you must take a nap, try to keep it short (less than one hour). Never take a nap after 3 p.m.

- **Keep a regular schedule.**

Regular times for meals, medications, chores, and other activities help keep the inner body clock running smoothly.

- **Avoid doing anything else in bed apart from sleeping and having sex.**

This includes reading, eating, watching TV, talking on the phone, playing games or surfing the internet.

- **Avoid caffeine, alcohol, cigarettes or strenuous exercise within six hours of your bedtime.**

- **Do not go to bed hungry, but don't eat a big meal near bedtime either.**

- **Avoid sleeping pills, or use them cautiously.**

Most doctors do not prescribe sleeping pills for periods of more than three weeks. Do not drink alcohol while taking sleeping pills.

- **Exercise regularly, if you can**

- **Make your bedroom quiet, dark, and a little bit cool.**

An easy way to remember this: it should remind you of a cave. Also make sure your bedding is comfortable.

- **If you think that worrying is keeping you awake, try some of the tips in the section 'Dealing with worry and anxiety' above.**

For example, you could try writing down your main worries in list form, and making a plan or 'to-do' list for those you can do something about.

- **Learn to relax**

You could try some relaxation or mindfulness exercises before bed, or whilst you are in bed and trying to sleep.

Asking for help

Although you will have regular contact with your health care team, there may be long periods between appointments and the majority of time you will be dealing with your cancer, the symptoms and side effects of treatment, by yourself. It is therefore important to make the most out of each appointment to ensure you get all the correct information you need. This will be especially helpful if you are feeling overly anxious or over-whelmed.

Here are some tips to help:

- Keep track of and write down all of your symptoms, even if they seem minor or unrelated to your NET. This includes new symptoms, changes in frequency or severity, and changes in your eating habits or routine.
- Write down questions or concerns between visits, so that you do not forget them, and bring them to the appointment, including questions about impact on work or holidays.
- Don't be embarrassed to ask the nurse or doctor to repeat or explain anything that you do not understand.
- Notice any thoughts stopping you from asking questions e.g., 'I am a burden' and use the strategies outlined above (e.g., thought challenging or mindfulness) to help you cope with them
- Bring records of previous tests/visits with you.
- Know your healthcare team and what each specialist's role or focus is.
- Don't be afraid to ask questions – ask why referrals, consultations or tests are being requested if you are unsure.
- Take notes during appointments to keep track of discussions.
- Bring a friend or caregiver with you for emotional support and to take notes.
- It can be hard to discuss emotions but it is important to let your healthcare team, and your trusted friends and family, to know if you are dealing with difficult feelings, since they can then point you towards appropriate sources of support.

Since NET is such a rare form of cancer, some health professionals may lack the specialist knowledge so if someone does not know the answer, ask them where you can go to find out.

Living and coping with NET can also be a difficult time for loved ones. They may want to help but be worried about saying or doing the wrong thing. You may also be worried about how to break the news to others. If you need further support with either of these issues, you can find some useful information and advice on the **MacMillan** website (see section below).

Where to find further support and information

If you are worried about having a serious anxiety disorder, or depression, then please talk to your healthcare professional about getting additional support.

If you have any questions about making changes to your diet, or have questions about this, then you can find a leaflet about nutrition on the NET Patient Foundation website (<http://www.netpatientfoundation.org/wp-content/uploads/037-NPF-NUTRITION-v3.pdf>). Alternatively, you can ask to see a specialist dietician, who provides input to the NET team at King's.

The **MacMillan Information and Support Centre** based King's College Hospital (<https://www.kch.nhs.uk/patientsvisitors/help-and-support/macmillan-information-and-support-centre>, telephone 020 3299 5229) is an excellent source of information and drop-in centre to provide help and support. They also provide free counselling sessions and complementary therapies such as meditation, acupuncture, reflexology, aromatherapy, massage and music therapy. You can also find a number of support leaflets on different topics here, as well as on their website: <http://www.macmillan.org.uk>.

Other useful websites include:

NHS choices: <http://www.nhs.uk/conditions/neuroendocrine-tumours/Pages/Introduction.aspx>

Cancer Research UK: <http://www.cancerresearchuk.org/about-cancer/type/rare-cancers/rare-cancers-name/what-are-neuroendocrine-tumours>

NET Patient Foundation: <http://www.netpatientfoundation.org>

Net Cancer Day (where you can find results of the first global survey of NET patients):
<http://netcancerday.org/>

The Carcinoid Cancer Foundation (for online support groups and forums): <http://www.carcinoid.org/resources/support-groups/online-support-and-discussion-groups>

Hopefully this leaflet has gone some way to helping answer some of your questions. If you have any further questions or concerns, please contact your clinical nurse specialist (CNS) using the details given on your CNS contact card and/or medicine booklet. These details can also be found at the top of your clinic letter.

King's Patient and Advice Liaison Service (PALS)

This is a service that offers support, information and assistance to patients, relative and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you. The PALS office is located on the ground floor of the Hambleton Wing, near the main entrance on Bessemer – staff will be happy to direct you.

Tel: **020 3299 3601**

Fax: **020 3299 3626**

Email: kch-tr.pals@nhs.net

The full range of IMPARTS booklets can be found at:

www.kcl.ac.uk/ioppn/depts/pm/research/imparts/Self-help-materials.aspx