

PRACTICAL ISSUES



**LOOK AFTER
YOURSELF
BY GETTING
PREPARED**

THE PRACTICAL STUFF

As we have said in previous sections, having a NET diagnosis can have an effect on all aspects of your life: this section looks at some of the practical, everyday aspects - from your ability to work to getting insurance to travel. We'll talk through some of the support that is available to help you with some of these practical challenges.

Work and NETs

One question many people ask after a NET diagnosis is 'Will I be able to keep on working?' The answer depends on your individual situation, of course, but often people are able to keep working for many years with a NET.

You do not have to inform your employer of your diagnosis, but it may help if you need to take time off now or in the future - for appointments or treatments. However before you do so, it may be worth checking your employment contract and discussing your situation with an advisor, such as a member of staff from Citizens Advice Bureau or Macmillan or your Professional Union.

Most employers are supportive, however others may not be. You are protected by law from unfair or unreasonable treatment or discrimination at work.

***The Equality Act 2010, or the Disability Discrimination Act 1995 (and its extension, the Disability Discrimination Order 2006 if you live in Northern Ireland), do not just apply to employees - job applicants and the self-employed are also protected.**

When you do decide to inform your employer it may be helpful to ask:

- What policies/information does the company have about this kind of situation?
- If required how soon can sick pay arrangements be confirmed?
- What kind of reasonable adjustments, if any, might be possible to help me do my job now?
- Should my health change - what reasonable adjustments may be possible?
- Can we discuss how or whether we will let other people, for example colleagues, know about my NET?

Once you've told your employer about your NET they have a duty to make 'reasonable adjustments' to make sure you are not at a disadvantage because of your illness.

Reasonable adjustments might include:

- Letting you have time off to go to appointments
- Changing your job description to remove tasks you may now find difficult
- Giving you extra breaks to cope with being tired
- Changing where you work - for example a change of office or department.

What is considered 'reasonable' depends on how much the adjustment will cost, how practical it is and how much of a benefit it will be, but failure to make adjustments could count as discrimination.

Most employers are willing to make changes - for example allowing you to work flexible hours - but if you find that's not the case it can help to ask a member of your care team to talk to your employer.

And remember that you have the right to privacy, so if you tell your manager about your NET but don't want your colleagues to know, your manager should respect that.

Talking to colleagues

It's up to you who you tell about your NET at work, but letting people know can help them understand what to expect and what support you might need. If your side effects mean you're often fatigued, for example, your colleagues may be able to help reduce your workload.

You may find that people act differently or seem awkward - just as you might experience when you tell your friends and family. Being open and letting people know if you're happy to answer questions or talk about your situation often helps.

Equally, you may decide you would rather not tell people at work about your NET. Some people find this is a useful way to cope because it helps this area of your life to feel more normal. If your symptoms or side effects increase, however, it may become more difficult to keep your illness to yourself.

Taking time off work

You may need to take days, weeks or a longer period off work during treatment for your NET. This may have a financial impact on your life - and we'll talk about some of the benefits and financial help that may be available to you in the next section.

If you do need to take an extended period off work, it may help to contact an independent financial advisor for suggestions on the best course of action. If you have private insurance such as income protection cover, mortgage protection or critical illness cover, you should contact your insurance company as soon as possible to begin making a claim.

It can also be useful to talk to your manager about what you would like to happen while you are away. You might prefer to forget about work completely while you focus on your treatment, or you might appreciate the odd email letting you know any news. Some people choose to visit work a few times while they are away to keep in touch and to get prepared before returning to work.

Working during treatment

Depending on the type of treatment you have, and the type of work you do, you might decide to keep working - especially if you're self-employed.

Ask your care team for advice if you are planning to keep working throughout treatment, and try and put a back-up plan in place if you do need to take some time off.

If you are self-employed

It can be a very difficult decision to take time off if you work for yourself. As well as worrying about paying the bills, you might be concerned about what will happen to the business you've invested so much time and energy in building up. Business groups and voluntary organisations offer a range of services to support small businesses, and you may be entitled to claim benefits if your income falls.

Useful contacts if you're self-employed

For information and advice, contact:

- Turn2us - www.turn2us.org.uk
- Citizens Advice - www.citizensadvice.org.uk
- The Money Advice Service - Freephone **0800 138 7777** (Monday to Friday, 8am to 8pm, Saturday 9am to 1pm)

Local Citizens Advice services offer advice from over 3,500 locations, in person and over the phone.

At the time of printing, a national phone service - Adviceline - is also being rolled out. It's currently fully operational in Wales for people who live or work there, and operational in some parts of England. If it's not yet available in your area, you will hear options for recorded information when you call.

To contact Adviceline:

- In England call 03444 111 444 or find local contact details via the search option at www.citizensadvice.org.uk
- In Wales call **03444 77 20 20**
- If you use TextRelay, call **03444 111 445**.

Macmillan also provides a wide range of information about work and cancer for employers, employees and the self-employed. To contact Macmillan, call **0808 808 00 00** (Monday to Friday, 9am to 8pm).

Returning to work

If you take time off work but feel ready to return after treatment, it can help to meet up with your manager (and an occupational health advisor, if there is one) beforehand to agree a 'return to work' plan.

This is a good opportunity to explain how you are feeling and to discuss any concerns. Many people find a phased return to work is the best option - to begin with you could work shorter shifts or not take on all of your usual responsibilities.

Try to avoid the temptation to immediately pick up where you left off. Allow yourself regular rest breaks and if you start to feel tired, let your manager know. If you feel you need to change the work that you do or alter your job description, you should discuss this with your employer as soon as possible. They have a duty to be flexible to help you carry on working.

If you have been claiming benefits while you were away from work, remember to let the Department of Work and Pensions know that you are working again.

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Taking early retirement

Rather than returning to work, you may want to take early retirement either for health or personal reasons. If you do that, it's essential to take advice from your pension administrator. Talking to an independent financial advisor is also recommended.

Depending on your pension scheme, you may be able to take early payment due to ill health.

If you have a pension scheme connected to your work, you may receive a higher amount of pension if you retire for health reasons, but if you're fit to work the amount you receive could be lowered.

BENEFITS AND FINANCIAL HELP

The financial costs of cancer can easily mount up, which can add to concerns about living with NET, but finding out if you are entitled to financial assistance such as benefits, grants and other monies can ease the strain.



There are lots of ways that living with a NET can affect your income.

Travel costs and parking charges can get expensive if you have regular hospital appointments. Your supermarket bill can go up if you're keeping to a different diet. If you need to work fewer hours or give up your job because of your illness, it can be difficult to cope with these additional costs.

Applying for benefits

The benefits system can feel like a maze, making it difficult to know what sort of help you may be eligible for - especially as benefit regulations change fairly often. Information on benefits can be found at: www.gov.uk/browse/benefits

However, we would strongly recommend that you speak to an expert before applying.

Staff at your local council and at charities including Citizens Advice and Macmillan can help to guide you through the process and give you up-to-date information.

Benefits related to your NET

UK legislation considers a cancer diagnosis as a disability. That's because - like many other health problems that may not be visible, such as mental health issues and severe fatigue - cancer has a substantial and long-term impact on your ability to do everyday activities.



The following information was accurate when this handbook was printed.

There are two main types of support available related to disability.

- **The Personal Independence Payment (PIP)** helps with some of the extra costs caused by long-term ill-health or a disability if you're aged 16 to 64. The amount you may receive depends on how your condition affects you, not the condition itself. You'll need an assessment to work out the level of help you get. Your rate will be regularly reassessed to make sure you're getting the right support. However, special circumstances may apply if your cancer diagnosis is advanced or high-grade

- The **Attendance Allowance** is a benefit for people aged 65 and over who have difficulty looking after themselves. You must have needed care for at least six months to be eligible for Attendance Allowance, and the amount you receive depends on the amount of care you need. Other benefits you may receive may increase if you get attendance allowance.

To apply for PIP or Attendance Allowance, you will need to complete a form explaining how your NET affects you and you may be assessed by an independent healthcare professional.

Your care team, GP and the NET Patient Foundation will be happy to support you through this process.

Other benefits and payments

There are a number of other ways you might be able to get financial help:

- **Statutory Sick Pay**, which will be paid by your employer for up to 28 weeks. You need to tell your employer that you are unwell no less than seven days after you become ill, and it's important to ask a GP (or your care team if you are in hospital) for a Statement of Fitness for Work to cover the time you are unwell. You may need this statement to claim benefits
- **Occupational or company sick pay**, which you may be able to claim in addition to Statutory Sick Pay - check your contract (or ask your HR team) for more information

- **Employment and Support Allowance (ESA)**. There are two types of ESA - one depends on how much national insurance you have paid, the other is related to your income. You may be eligible for either or both, depending on your income, savings and national insurance contributions
- Alternatively, depending on your situation and where you live, you might need to apply for Universal Credit instead of ESA
- If you're **self-employed**, you may still qualify for Employment Support Allowance or **Universal Credit**
- If you're not able to keep working because of your NET or if your earnings drop, you might be entitled to an **income tax refund**
- **Income Support** if you're aged between 16 and the State Pension age. This will depend on your savings, the number of hours you work and your household costs. (Income Support is gradually being replaced by **Universal Credit**)
- **Working tax credit** - a means tested state benefit payment available to those who are working (either employed or self-employed) and on a low income. This is also being replaced by **Universal Credit**.

If you are caring for someone with a NET...

Organisations such as Carers UK can guide you through what's available - as well as offering practical advice on looking after yourself while caring for someone else.

Financial help for carers includes:

- **Carer's Allowance**, a weekly payment based on criteria including the number of hours you spend caring for someone and your weekly earnings. The person you care for must receive Attendance Allowance, Disability Living Allowance or the Personal Independence Payment for you to qualify for Carer's Allowance
- **Carer's Credit**, which provides national insurance credits if you need to take time off work to care for someone. This prevents shortfalls in your national insurance payments that could affect your State Pension entitlement.

Additional financial help

Some charities offer one-off grants to help people cope with the costs of cancer, and schemes such as the NHS Low Income Scheme might enable you to claim back travel expenses if you are on a low income.

Some hospitals also offer reduced parking charges for people with cancer, and schemes exist to help you buy or hire cars, scooters or powered wheelchairs, if you are eligible for certain benefits.

Your care team, staff at the NET Patient Foundation and advisors at charities such as Citizens Advice and Macmillan will be able to let you know what may be available and who to contact to access these schemes.

TRAVELLING AND NETs

Whether you need to take a trip for work, a mini-break or just want to get away from it all, you can reduce the stress of travelling and look after yourself by getting prepared in advance.

If you love to travel, there's no reason why trips in the UK or overseas should be any less enjoyable if you have a NET. They can be the perfect way to relax and reflect - you just might need to spend a little more time planning your trip than usual.

Talk to your care team

If you're planning a holiday to get away from appointments and hospitals for a while, you should speak to your doctor or specialist nurse before planning your trip.

They can let you know if you're fit to travel and give you documents you might need if your destination is overseas - like copies of your prescriptions, confirmation of fitness to travel (required by some airlines) and a basic report explaining your condition, your medication and your care needs. (It's a good idea to get these translated into the local language(s) before you travel.)

They can also talk you through any precautions you may need to take depending on where you're travelling to and for how long. They can discuss with you the best time for you to travel if you're currently having treatment.

And as well as speaking to your UK care team, you can check out whether there is a NET service in the area or country to which you are travelling.

Call our NET Patient Foundation freephone number - **0800 434 6476** - to find out more or for an up-to-date list of UK and European NET Centres of Excellence visit:
www.enets.org/coe_map.html

Take your side effects into account

If you're often tired at certain times of day or get fatigued easily, can you arrange your travel schedule to take account of this? If you need to eat a special diet, will the food and drink you need be easily available where you're going? If you have diarrhoea, how easily can you control it and what facilities are available during your journey and at your destination?

Asking yourself questions like these and arranging your trip around any issues can stop symptoms or side effects from limiting your enjoyment. Your care team will have plenty of ideas if you're worried about specific problems.

Make special arrangements in plenty of time

Will you need help getting on and off planes, trains or ships? Would it help to arrange early boarding if you're flying? Do you need help walking or climbing stairs?

Many travel companies have medical officers who can offer practical advice, and contacting airlines, train companies, tour companies and hotels before travelling makes it much easier to ensure help is available where needed.

Preparing for your trip

Vaccinations

Ask your care team for advice if you're thinking of travelling somewhere that means you'll need vaccinations.

Vaccinations reduce the risk of getting ill while you're travelling, but you may not be able to have them (or may have to wait to have them) if you've had treatment that can affect your immune system - for example chemotherapy or radiotherapy.

That's because some 'live' vaccines contain small amounts of viruses or bacteria, and if your immune system is suppressed these can make you ill. Other types of 'inactive' vaccines don't contain live viruses but may be less effective if your immunity is lowered.

Travelling with medication

Make sure you have enough medication for your whole trip - but check any restrictions before you travel on medication you need to take with you, because some countries will not allow you to bring certain medications in.

Carrying morphine or medications that contain codeine without a prescription can be a criminal act. Contact the embassy or high commission of the country you're visiting to find out more.

If you do travel with medication, carry it in your hand luggage in the original container and packaging, because customs officers may want to see it. And if you're travelling with a licence for controlled drugs or with letters from your doctor, make sure you keep those in your hand luggage too.

If you're travelling for more than three months and have medication for that length of time, you may need to get a personal medicine licence from the Home Office Drugs Licensing and Compliance Unit - visit www.gov.uk for more information.

Remember that you may need to buy small cool bags (available from chemists) to carry medicines that you need to keep cool. Make sure to check that there's a fridge you can use at your destination, too.

And it's a good idea to carry a list (and email it to yourself) of all the generic names of any drugs you're taking, along with your doses, in case you need to find more when you're overseas. Brand names of drugs can vary, so the names you're used to might not be recognised elsewhere.

Speak to your pharmacist about when to take medication if you're travelling across time zones. It might be easiest to gradually shift to fit with the local time.

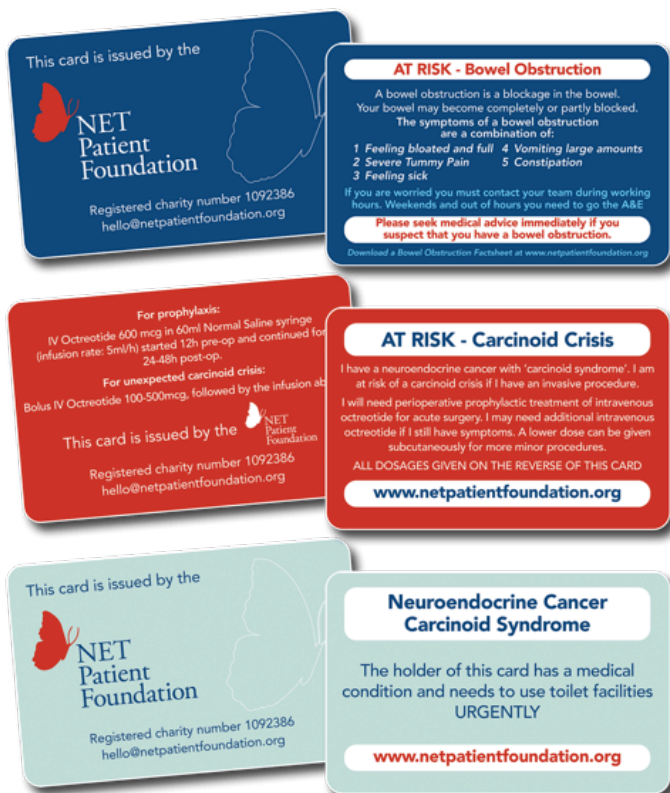
MediAlert and carcinoid crisis cards

Before travelling, you might want to get a MediAlert disc or bracelet so that doctors know about your NET if you need urgent medical attention.

Alternatively, if you are taking your mobile phone with you - basic information, such as your diagnosis, allergies, medications and carcinoid crisis protocol can all be stored in the emergency information facility. This can be accessed by emergency responders, even if you have a lock screen activated.

If you are not aware of this facility, please refer to the handbook for your device or contact the manufacturer, to find out more.

The NET Patient Foundation also provides wallet alert cards highlighting the risk of carcinoid crisis or bowel obstruction. We also provide another card to explain that your NET means you may need to use the toilet urgently. You can get these by calling us at the NET Patient Foundation on **01926 883487**.



Travel checklist

- Medication in original packaging
- MedicAlert disc or bracelet
- NET Patient Foundation wallet alert card(s)
- Doctor's letters, certificates and licences
- Copies of your prescriptions
- Extra medical supplies
- Travel insurance policy and documents
- List of your medication, with doses and including generic names
- Cool bags for medications
- Passport and proof of UK residence (e.g. driver's licence)
- European Health Insurance Card (if you're travelling to the EEA or Switzerland)
- Name and contact details of local NET service (if there is one)



Staying healthy during your trip

Diarrhoea and sickness

Diarrhoea and nausea may be symptoms you usually experience. If that's the case, you should be able to deal with this as you normally would at home - for example by increasing your medication or adjusting your diet. NB if uncertain about the quality of drinking water - drink bottled water only.

Diarrhoea and sickness that start or increase while you are travelling can ruin a trip and be potentially serious. Here are some precautions you can take to avoid these travel-related issues:

- If you're worried that water might not be clean, avoid ice in drinks and salads that may have been washed in tap water, drink only bottled water (make sure the lids are sealed) and boil all water before you clean your teeth
- Don't drink unpasteurised milk or eat ice-cream made with unpasteurised milk
- Always eat food that is fresh and avoid raw food if you have any concerns about it
- Ensure your food is thoroughly cooked and still hot. If you have any doubts, don't eat it!
- Avoid food that has been left in the open air, reheated or exposed to flies
- Try not to swallow water if you are swimming (in pools, lakes, rivers and the sea).

Staying safe in the sun

Protecting your skin from the sun is always important, and some treatments can make your skin more sensitive, meaning it's even more important to

follow the usual advice. So if you're out in the sun:

- Use sunscreen that has a high sun protection factor - reapply at regular intervals
- Stay out of direct sunlight, especially during the hottest times of the day
- Wear a wide-brimmed hat
- Spend plenty of time in the shade
- Wear loose clothing made of cotton or natural fibres
- Drink plenty of water.

Your care team will give you specific advice if you NET treatment is likely to have increased your sensitivity to the sun.

Getting healthcare abroad

At the time of publication (in 2016), if you're visiting a country in the European Economic Area (that's all EU countries plus Iceland, Liechtenstein and Norway) or Switzerland, you should apply for a free European Health Insurance Card online before travelling. These entitle UK residents to free or reduced-cost health treatment in these countries.

Some other countries, including Australia, New Zealand, Barbados, Jersey and Russia have reciprocal healthcare agreements with the UK, meaning treatment will be free or the cost will be reduced.

Elsewhere, you may well need to pay for the full cost of healthcare, which is why it's important to take out comprehensive travel insurance.

Before you travel, search online to find out if there is a NET service close to your destination.

INSURANCE

Travel insurance

It can be difficult or expensive to get travel insurance after you've been diagnosed with cancer, and searching for comprehensive cover can be frustrating. However, there are reputable companies who will provide cover for NET patients at reasonable cost.

Please either contact us for further details by calling the freephone NET Patient Foundation number - **0800 434 6476** or visit our website for NET patient experiences and recommendations.

You can also get in touch with other people with NETs - for example via our Facebook page or forum - to find out which insurers they have had good experiences with recently.

Once you've found companies that could help, we'd recommend you phone to discuss your situation rather than using an online application form. Ask to speak to a senior insurance consultant, and have information from your care team with you so you can explain exactly what your situation is.

Many insurers do struggle to understand what NET is, and how it behaves and may affect those living with it, but with persistence you can find companies do get it, and will give you the cover you need at reasonable cost. Make sure you allow plenty of time to search for the best deal and when you find it, spread the word!

Life insurance

Like travel insurance, life insurance becomes more expensive and harder to find once you've been diagnosed with a NET.

If you try to buy life insurance cover following a cancer diagnosis, you will usually have to pay an above-average premium. Some insurers may refuse to insure you altogether. To get the clearest picture of your situation, it may be worth seeking independent financial advice before speaking to insurance companies.

Whether or not you are able to get cover usually depends on the type of cancer you have and what stage it is at, so when you apply for policies make sure you speak to insurance consultants over the phone (rather than applying online) and have all of the details of your condition handy - staging, grading, function etc. Your insurer will want to see a medical report and may ask you to have a medical assessment.

Some insurance companies and brokers specialise in cover for people with cancer and/or incurable illnesses, so again it's worth asking for recommendations at our Facebook page and our online forum. Remember, though, that an insurer will always make a decision based on your individual situation.

DRIVING AND NETs

When do you need to let the DVLA know that you've been diagnosed with a NET?

For car and motorcycle licences

You'll need to check with your care team about your specific situation, but (at the time of printing) you don't need to tell the DVLA you have cancer unless:

- Your care team says you are not fit to drive
- You develop problems with your brain, nervous system or blood sugar control
- You're restricted to certain types of vehicles or vehicles that have been adapted for you
- Your treatment and medication causes side effects that could affect your driving.

It's your responsibility to tell the DVLA if your NET could affect your driving, and you can be fined up to £1,000 if you don't let them know - and prosecuted if you're in an accident.

If you're advised not to drive for a short period of time - for example after surgery - you do not need to inform the DVLA. However, driving when you've been advised not to by your care team will invalidate your insurance.

Remember if your situation changes and you're told to contact the DVLA, you must make that call.

If you do need to tell the DVLA about your condition, you need to fill in form G1, which is available at www.gov.uk/cancer-and-driving or in Post Offices.

For bus, coach and lorry licences

You must tell the DVLA if your condition will affect your driving if you hold a bus, coach or lorry licence. In that case you'll need to fill in form C1V.

Check your car insurance

Whether or not you need to tell the DVLA, it's worth looking at your car insurance policy to find out whether you need to let your insurance company know about your NET. Some policies are no longer valid if you don't let your insurers know about a change in your health.

For the latest information on when you must tell the DVLA about your health, head to www.gov.uk/cancer-and-driving

To speak to an advisor at the DVLA drivers' medical enquiries service, call 0300 790 6806 (Monday to Friday, 8am to 5:30pm, Saturday, 8am to 1pm).