NHS
Royal Devon
University Healthcare
NHS Foundation Trust

Patient held records

Immunotherapy

(Eastern services)

Other formats

If you need this leaflet in another format such as audio CD, Braille, large print, high contrast, British Sign Language or translated into another language, contact the Patient Advice and Liaison Service:

- 01392 402093 (for Mid Devon, East Devon and Exeter services)
- 01271 314090 (for North Devon services)
- rduh.pals@nhs.net

Details about you

Name:	
Unit Number:	
Consultant:	
Specialist Nurse:	
Drug allergies:	

IF YOU ARE SUDDENLY STRUGGLING TO BREATHE OR HAVE CHEST PAIN, THIS IS AN **EMERGENCY** AND YOU SHOULD **PHONE 999** AT ANY TIME.

- PLEASE CONTACT US IF YOU ARE EXPERIENCING ANY OF THESE SYMPTOMS;
    - Shivering/shaking/temperature
    - Sudden loss of control of your bladder or bowels, leg weakness
    - Vomiting – more than four times in 24 hours

  - Diarrhoea – more than four times in 24 hours
  - Unusual bleeding or bruising
  - Sudden onset of swollen/painful legs or arms
  - Sore mouth where you are unable to eat or drink
- Have any other side effects.
- Have questions regarding your treatment

Contact numbers

Non-urgent Advice line: 01392 402876 (answer phone)
Monday – Friday 08:00 –17:00

Nurse for Urgent advice: 07825 401059
24hours Inc. weekends and bank holidays

Appointment queries: 01392406181

Consultant secretary:

CNS Team:

Anti-cancer treatment record

To be completed as fully as possible by staff prescribing/giving anti-cancer treatments.

Treatment Regimen:	**Check**	**Date**
Consent – undertaken by doctor		
Patient information given verbally		
Patient information given in documentary form		
Contact details for the CNS		
Alert card issued		

Treatment Regimen:	Check	Date
Consent – undertaken by doctor		
Patient information given verbally		
Patient information given in documentary form		
Contact details for the CNS		
Alert card issued		

Treatment Regimen:	Check	Date
Consent – undertaken by doctor		
Patient information given verbally		
Patient information given in documentary form		
Contact details for the CNS		
Alert card issued		

What is Immunotherapy?

Immunotherapy treatments work with your body's immune system. The treatment makes you immune system better at acting against cancer cells. The side-effects of immunotherapy are normally mild and don't happen often., When side-effects do happen they can be serious and even life threatening, so it is important to notice and treat them quickly. Side effects include:

- Rash, itchy or dry skin
- Colitis (crampy tummy pain, diarrhea and, rarely, bleeding)
- Pneumonitis (cough and shortness of breath)
- Hepatitis (liver blood tests abnormal)
- Adrenal insufficiency (endocrine blood tests abnormal)
- Hyper/hypothyroidism (endocrine blood tests abnormal)
- Hypophyses (endocrine blood tests abnormal)
- Renal insufficiency (kidney blood tests abnormal)

Immunotherapy works with part of the immune system called the T cells. The T cells normally find and attack cancer cells. Some cancer cells send out chemical signals that stop these T cells working. Therefore the cancer cells stay 'hidden' and are allowed to grow. Immunotherapy helps to stop these chemical signals so the T cells can find and attack the cancer cells.

We want to support you, so please ask the doctors and nurses involved with your care to discuss any questions you have about your immunotherapy.

The **Immunotherapy Clinical Nurse Specialist team** will support you during your treatment. You can talk to them about any questions or concerns that you have. You can contact the team directly on: 07717 806220 (08:30 – 16:30) or via the Acute Oncology non-urgent advice line number: 01392 402876.

Information for you and your health professional

These immune-related side-effects are often different from the side effects related to other cancer treatments, so it is important that you and all your doctors know how to recognize and manage them. Please hold onto this information during your treatment and present it to any health professional if you are unwell.
Details of your treatment will be sent to your GP by your oncology consultant and after each pre-treatment review.

FOR YOUR DOCTOR

https://www/clatterbridgecc.nhs.uk/professionals/guidance
or ukons ao initial management guidelines final version 2023.pdf

How to use this booklet

This is your anti-cancer treatment record to keep. It can help you to be more involved with your care and improve the communication between the healthcare professionals who look after you.

This booklet tells you about:

- FORCE
- ELF
- Macmillan
- Anti-cancer treatments
- Complications of having treatment
- Sex, pregnancy and family planning
- Contact numbers
- Things to tell your doctor

Your doctors and nurses will use this booklet to:

- Record details of your treatment

To help your doctors and nurses, please:

- Make a note of any side-effects you have during treatment.
- You may also like to make your own notes.

This information has been designed to help you understand more about the treatment that has been prescribed for you. There will always be some unanswered questions and we hope this booklet will help fill some of the gaps.

Information

A diagnosis of cancer can provoke a variety of reactions. When first told, you may feel a mixture of emotions such as shock, fear, anger or disbelief. You may feel nothing at all. Suddenly life seems very different. All of these feelings have been well-described by people in this situation. It can also have a profound effect on those close to you who may be feeling similar emotions.

This first reaction will subside, but coming to terms with the situation and learning how to cope can be stressful and will always be individual.

Having information and feeling supported can help reduce uncertainty, anxiety and depression. Do not be afraid to ask questions or ask for information. Knowing more about YOUR diagnosis and treatment can help reduce anxiety and help you feel in control.

Remember that advances are being made in cancer care all of the time. What you or your family and friends think you know may not be correct or up-to-date. Always check whether you have understood what you have been told, and ask for explanations if necessary. Being given information, feeling supported and having the opportunity to talk things through can all have a place in adjusting to a diagnosis of cancer.

If you have any questions or issues you would like to discuss, please ask the healthcare professional who will be looking after you. They are specially trained both to plan and deliver your treatment and to care and support you throughout.

Additionally, you can contact either the ELF councillor (Haematology patients) or FORCE Cancer Support Team if you would like someone to talk to you.

- ELF: **01392 493344**
- FORCE: **01392 406151**

Many books about the different cancers, their treatments, and side effects are available at the hospital, ELF, the FORCE Cancer Support Centre or from Macmillan UK, Europe's leading cancer information and support organisation (**www.macmillan.org.uk**).

Did you know...?

The FORCE Cancer Support Centre is based in the grounds of the RD&E Hospital (Wonford)

(Find us in the hospital site map.)

We provide:

Information; Support and advice;
Complementary therapies;
Welfare Benefits Advice; Wig Fitting;
Relaxation classes; Refreshments

Our services are FREE to anyone affected by cancer

Why not drop in or call us on

01392 406151

www.forcecancercharity.co.uk

Cancer charity force

Registered Charity No. 296884

working locally to support anyone affected by cancer

Exeter Leukaemia Fund

A diagnosis of a blood cancer or blood disorder is life changing and affects not just the patient but those closest to them.

Here are some of the services that ELF provides ...

Transport Service

ELF's transport service takes Haematology patients door to door, easing the anxiety of transport concerns. Although a free service, a donation helps keep the service 'on the road' and would be greatly appreciated.

Accommodation

The ELF flat offers accommodation to patients and their families, making early or late appointments more manageable, or allowing families to stay close by when a loved one is admitted.

Advice services

ELF works with the Citizen's Advice Bureau to make sure that patients receive the very best advice. Ask us how the CAB could help you.

To find out how the above ELF services can help you or your family – please call Debbie on 01392 493344

Counselling

ELF's counselling service provides a safe space for patients discuss the emotional demands of their condition.

Therapist

The ELF funded Generic Therapist helps patients cope with the impact of their treatments and makes sure that the patient's physical and emotional needs are met.

ELF@Home

ELF is introducing one-to-one befriending service. Trained volunteers will offer emotional and practical support tailored to the needs of patients and their families. The new service is being piloted in East Devon.

To find out more about ELF@Home call Sue on 07841 027228

Pop into the ELF Office, located in Haematology Reception, for more information or to talk to us about how we might be able to help.

Supporting Patient Journeys

enquire@elfcharity.org.uk Tel: 01392 247725 www.elfcharity.org.uk
Facebook.com/elfcharity Twitter: @elfcharity Registered CIO 1154727

elf exeter leukaemia fund

How will I feel during my treatment?

The fact that you need to have treatment, and the affect it has on your life, can prompt a range of feelings; fear, anxiety and depression are common to many people with cancer and are entirely normal. This may be in addition to how you feel physically. Some people find it helps to gather information about their disease and treatment because this lessens the fear of the unknown. Find out as much as you want to know and do not be afraid to ask questions.

Your emotional wellbeing is as important as your physical health. Many people do not understand about cancer or its treatment and may avoid you because they are not sure what to say or how to help. Try to be open in talking with others about your illness, treatment, needs and feelings.

Loss of concentration may be a side effect of treatment. This can affect your ability to listen and remember things which are explained at your visits. Do not feel embarrassed to ask for information to be repeated as often as you need it. Some people find it helpful to make a note of questions before their appointment, or make notes during an appointment.

You may find it helpful to bring a friend, partner or relative to your hospital visits. The doctors and nurses caring for you will be happy for you to do this.

Health needs assessment

During your initial diagnosis, many concerns and anxieties could occur.

To help us understand some of your concerns, we will give you the opportunity to complete an ‘Electronic Health Needs Assessment’ or ‘Integrated Palliative Care Outcome Scale’ at times appropriate to you. This will help us identify areas of help or support you might need; they might be practical, personal, family related, spiritual/religious or physical.

The assessment is available through your Clinical Nurse Specialist. It will help highlight any particular difficulties you may have at the moment as a result of your cancer diagnosis and treatment. It enables you to discuss a plan of action with your nurse, who can suggest an appropriate service and refer you if necessary.

Enhanced supportive care team

The doctors or nurses involved in your care may suggest a referral to the Enhanced Supportive Care Team. You can also ask for a referral yourself if you think their service may be of benefit to you. The team is made up of a number of healthcare professionals including doctors, nurses, physiotherapists, occupational therapists and dieticians all trained in supportive and palliative care.

Early integration of supportive and palliative care has been shown to better manage the side effects of

anti-cancer treatments and enable more informed discussions regarding treatment options.

The enhanced supportive care team work alongside your Oncologist and Cancer Nurse Specialist to help manage symptoms you are experiencing. They may invite you to discuss your thoughts and wishes for the future.

They will also play a vital part in liaising with your GP, district nurses and community palliative nurses to ensure your plan for care is delivered seamlessly between different settings.

Vaccinations during immunotherapy treatments

We recommend that you have the seasonal “flu” vaccine if you are about to start or are already receiving treatment for your cancer.

Ideally it should be given prior to starting a course of treatment. However, it is safe for you to have the 'flu' vaccine whilst having immunotherapy but please avoid the three days before and after treatment.

Live vaccines such as MMR, Shingles (Varicella Zoster) and BCG should be **avoided** before, during and for up to six months after immunotherapy treatment. Please check with your doctor if you are unsure.

Medical exemption certificates

As a patient receiving treatment for cancer you are eligible for an exemption certificate for free prescriptions. This is valid for five years and can be renewed as many times as necessary.

Visit your GP surgery and fill in an exemption form, your GP will sign this. Following the posting of this form you will receive a card. This card can be presented at pharmacies and you will not be required to pay for prescriptions.

Dental treatment

If you think you require any dental work whilst receiving treatment for your cancer, please ensure you speak to your doctor or nurse prior to booking your dental appointment. This is particularly important if you are receiving any bone-strengthening drugs.

Patients with a known low platelet count should seek advice from their nursing team prior to having dental treatment.

If possible book a dental assessment prior to starting your treatment or if you are due some dental work please let us know.

Physical activity during and after treatment

In the past, during treatment, doctors advised people to rest as much as possible: this has changed!

Evidence now shows that simple physical activity can reduce many of the side-effects of treatment and also the risk of recurrence in some cancers.

Being active during and after treatment can:

- Reduce tiredness/fatigue
- Reduce stress and anxiety
- Help look after your heart and bones
- Help keep your weight healthy
- Improve sleep patterns

Any amount of exercise is better than none at all. You can be active by simple day-to-day activities such as walking, or by using more-structured exercise programmes that you might do at home or in a gym.

There is no single activity that is best for everyone. Choose an activity you enjoy that fits in with your life and level of fitness.

For haematology patients a generic therapy practitioner is available who can support exercise, mobility, physical issues and coping at home. They can offer one-to-one and group information and exercise sessions. Please speak to a member of the haematology nursing staff for further details.

FORCE, the Exeter cancer charity, can support you with information and advice about exercise from a specialist physiotherapist, or introduce you to an eight week exercise programme that is available at a choice of venues. Please ask your nurse to refer you to FORCE, the Exeter cancer charity, or refer yourself. Call FORCE on 01392 406151.

Sex, pregnancy and family planning

Having a cancer diagnosis doesn't mean that you shouldn't have sex, but you may not always feel like it.

If you are planning to have a family in the future please talk to your hospital doctor about this. Pregnancy should be avoided while receiving immunotherapy treatment. If you or your partner receives immunotherapy drugs just before or during pregnancy, they may harm the developing baby.

Cancer treatment can reduce fertility, especially in men. It may make some people infertile, either temporarily or permanently, although this is not always the case. So, during your treatment always use a contraceptive if you are a female of child-bearing age or a male.

If your period is late and you think that you may be pregnant, tell your doctor straight away.

Extravasation

Introduction

Your treatment will involve having drugs put directly into your blood stream; this may involve you having a cannula placed in your forearm or hand. Whilst the majority of these devices are used without problems, just rarely there is a complication called extravasation.

What is extravasation?

Extravasation is the term used to describe the leakage of a drug out of the vein into the surrounding tissue.

What causes extravasation?

The exact cause is not always clear, but we know that some people are more at risk than others.

What are the symptoms?

You may notice redness, inflammation or irritation, warmth, pain, stinging or swelling at or near the site where the drug enters the vein.

Fortunately, more severe symptoms are very rare.

How can it be prevented?

We can reduce the risk by careful choice of the type of cannula used and where it is placed in the hand or arm. The possibility of extravasation occurring cannot be completely prevented.

This is why it is so important that you let staff know immediately of any change in sensation around the cannula whilst treatment is being given.

How is it treated?

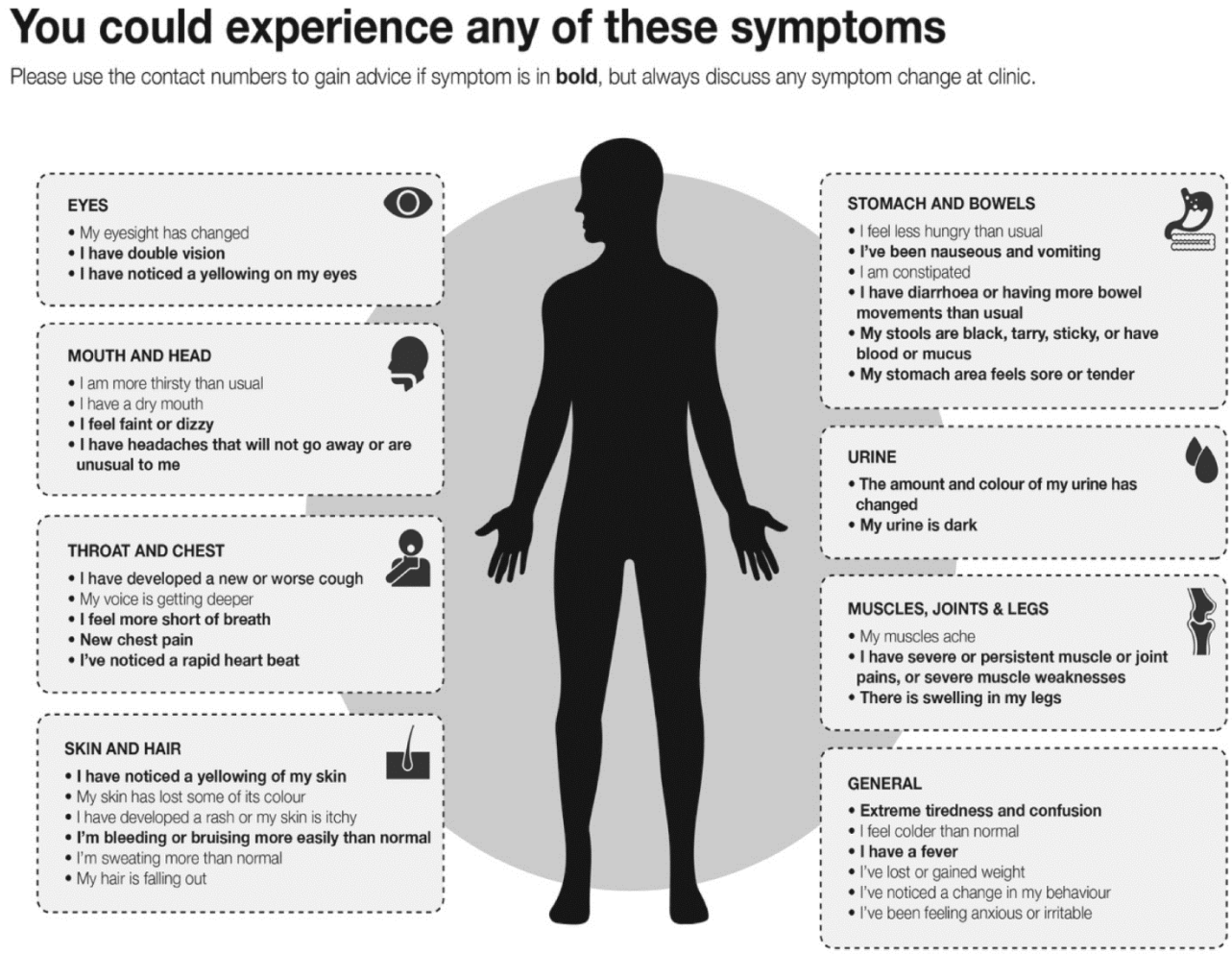
The Trust has a clear policy on the management of extravasation and the treatment required for the different drugs used.

If an extravasation does happen you will be provided with an information leaflet on your condition and how to care for your injury.

If you have any further questions or concerns please seek advice from a member of the nursing team.

Side effects

Although not experienced by everyone, some medicines can cause unwanted reactions which are commonly called side-effects. If you experience side-effects then it is very important that you report these to your hospital team, as soon as you identify them. Delay in reporting side-effects may result in them becoming worse and potential treatment interruptions may occur.



The next couple of pages grade potential side effects that you may experience from Immunotherapy into Red, Amber and Yellow boxes.

Please contact the treatment unit **immediately** if your symptom is graded within the **Amber** or **Red** boxes.

Please contact Cherrybrook or Yarty daycase during their opening hours if your symptom is within the **Yellow** box.

Traffic light symptom reporting tool for immunotherapy

	GREEN	YELLOW	AMBER	RED
Symptom	**None / No more than usual**	**Mild / Occasionally**	**Moderate / Often**	**Severe**
Diarrhoea	No change from normal	Bowels open more than usual for you but less than 4 times a day with no blood or pain.	Bowels open between 4-6 times daily with or without pain/blood.	Bowels open more than 6 times daily and severe abdominal/stomach pain
Breathing	Breathing/ cough no different from usual.	Mild cough or change in cough, some shortness of breath on movement	Troublesome cough, worsening shortness of breath on movement	New shortness of breath when just sitting
Fatigue	Relieved by rest	Not relieved by rest and beginning to reduce the ability to do daily activities	Not relieved by rest and assistance required with self-care	Bed bound
Urine	No change from normal	Urine causing burning or stinging	Urine much darker than usual or passing lots more urine than normal	Passing blood in urine
Symptom	None / No more than usual	Mild / Occasionally	Moderate / Often	Severe
Loss of appetite / nausea	Loss of appetite but still eating normally	Reduced oral intake without significant weight loss or dehydration	Not eating properly and feeling sick	Not able to keep food/fluids down.
Skin	No change from normal	Rash or itchiness covering less than 10% of body, peeling or dry skin	Rash covering up to a quarter of the body with or without itching	Rash covering more than quarter of the body with or without itching
Excessive thirst	None/No more than usual			Excessive thirst, dry mouth and passing much more urine than normal
Eye pain	None/No more than usual			Redness, dislike of bright lights, blurred vision, symptoms worsening over a few hours/days

	GREEN	YELLOW	AMBER	RED
Symptom	None / No more than usual	Mild / Occasionally	Moderate / Often	Severe
Feeling weak, drowsy, dizzy or faint	None/No more than usual			Unable to stand up or get out of bed for long periods Headaches (adrenal symptoms)
Weakness of facial muscles	None/No more than usual			Eyelid drooping, double vision, symptoms worse towards end of day
Weakness in feet and rising up legs	None/No more than usual			Weakness or loss of sensation in lower limbs

Date	Cycle No.	Drug and dose	Supportive drugs

Date	Cycle No.	Drug and dose	Supportive drugs

Date	Cycle No.	Drug and dose	Supportive drugs

Date	Cycle No.	Drug and dose	Supportive drugs

Blood results

Date	Hb	WBC	Neut	Plt	Creat	Bili	TSH	Cort	

Blood results

Date	Hb	WBC	Neut	Plt	Creat	Bili	TSH	Cort	

Blood results

Date	Hb	WBC	Neut	Plt	Creat	Bili	TSH	Cort	

PICC care plan

Please fill in the chart below to indicate which tasks have been completed.

Date	Dressing & bung changed	Statlock changed	Aspirated & flushed	Any other information	Sign

Patient notes

Patient notes

Patient notes

Patient notes

Patient notes

Patient notes

Information and support

Many books about the different cancers and related topics such as diet and travel insurance are available from:

- **FORCE Cancer Support Centre: 01392 406151**
  Force is based in the grounds of the Hospital – offers support and information to anyone affected by cancer

  www.forcecancercharity.co.uk

- **Exeter Leukaemia Fund (ELF): 01392 493344**
  ELF are based / have a base in the Haematology waiting room – dedicated to helping patients with blood cancer or a blood disorder

  www.elfcharity.org.uk

- **Macmillan: 0808 808 0000**
  (Macmillian is a national organisation offering cancer information, support and resources

  www.macmillan.org.uk

Cancer may bring about changes in your life and can present difficult and sometimes distressing challenges. It is common to experience all sorts of different emotions such as fear, anger, sadness or even depression.

Many people receive support from their spouse, partner or family member; sometimes it can be beneficial to seek additional help.

FORCE Cancer Support Centre

There are two **FORCE Oncology Support Specialists** available in the hospital and they can be contacted on **01392 402866**. Alternatively, you can visit the FORCE Cancer Support Centre in the corner of the hospital grounds. The Centre offers a whole range of services to anyone affected by cancer.

Talking to a counsellor, joining a support group and/or learning a relaxation technique can relieve anxiety and help you cope more effectively. Complementary therapies can also reduce stress and promote physical and emotional wellbeing and are available to both men and women . Look Good, Feel Better sessions are available for patients who identify as female.

You can simply drop in between 9:30am and 4:30pm or call on **01392 406151** for further information about the centre.

Exeter Leukaemia Fund – Supporting Patient Journeys

We can help with transport, accommodation and fast-tracked Citizens Advice Bureau appointments.

Our counsellor offers support to patients and their families, either individually or in groups.

Our one-to one befriending service ELF@Home is currently being trialled in East Devon and offers emotional and practical support to patients and their families.

The ELF Office, located off the haematology waiting room, is open between 8:30 and 16:00. Please ring **01392 493344** or email debbier@elfcharity.org.uk.

A support group is available for haematology patients. Please liaise with your support worker or CNS for further information.

Alternatively you can talk to a nurse at Macmillan FREEPHONE: **0808 808 0000**

PALS

The Patient Advice and Liaison Service (PALS) ensures that the NHS listens to patients, relatives, carers and friends, answers questions and resolves concerns as quickly as possible. If you have a query or concern, please contact PALS:

- 01392 402093 (for Mid Devon, East Devon and Exeter services)
- 01271 314090 (for North Devon services)
- rduh.pals@nhs.net

Have your say

Royal Devon University Healthcare NHS Foundation Trust aims to provide high quality services. However, please tell us when something could be improved. If you have a comment or compliment about a service or treatment, please raise your comments with a member of staff or the PALS team in the first instance.

You can also share your feedback on the Care Opinion website at www.careopinion.org.uk or freephone 0800 122 3135.

Scan the QR code to visit the Care Opinion website →

Royal Devon University Healthcare NHS Foundation Trust
www.royaldevon.nhs.uk

The Trust cannot accept any responsibility for the accuracy of the information given if the leaflet is not used by Royal Devon staff undertaking procedures at the Royal Devon sites or in community settings.

© Royal Devon University Healthcare NHS Foundation Trust
This leaflet was designed by the Graphics Department.
www.royaldevon.nhs.uk/get-in-touch