

## Seek advice from other agencies

### England

In England, the Patient Advice and Liaison Service (PALS) provides information and support on health-related matters.

<https://bit.ly/3L2kfaR>

### Northern Ireland

In Northern Ireland, the Patient and Client Council provides an advocacy service.

<https://pcc-ni.net/advocacy>

### Scotland

In Scotland, the equivalent service is the Patient Advice and Support Service (PASS), delivered by the Citizens Advice Bureaux.

[www.cas.org.uk/pass](http://www.cas.org.uk/pass)

There is also an online directory of health and wellbeing services in Scotland. [www.nhsinform.scot/scotlands-service-directory](http://www.nhsinform.scot/scotlands-service-directory)

### Wales

In Wales, the Patient Advice and Liaison Service (PALS) provides information and support on health-related matters.

<https://bit.ly/3L2ku5L>

### UK

Across the UK, Citizens Advice can advise on benefits and other financial and legal issues.

[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

Immunodeficiency UK has leaflets on a wide range of topics, as well as a helpline.

[www.immunodeficiencyuk.org](http://www.immunodeficiencyuk.org)

## About Immunodeficiency UK

Immunodeficiency UK is a national organisation supporting individuals and families affected by primary and secondary immunodeficiency.

We are the UK national member of the International Patient Organisation for Primary Immunodeficiencies (IPOP), an association of national patient organisations dedicated to improving awareness, access to early diagnosis and optimal treatments for patients worldwide.

Our website at [www.immunodeficiencyuk.org](http://www.immunodeficiencyuk.org) provides useful information on a range of conditions and topics, and explains the work we do to ensure the voice of primary and secondary immunodeficiency patients is heard.

If we can be of any help, please contact us at [hello@immunodeficiencyuk.org](mailto:hello@immunodeficiencyuk.org) or on **0800 987 8986**, where you can leave a message. Visit [www.immunodeficiencyuk.org](http://www.immunodeficiencyuk.org) for further information.

Support us by becoming a member of Immunodeficiency UK. It's free and easy to do via our website at [www.immunodeficiencyuk.org/register/](http://www.immunodeficiencyuk.org/register/) or just get in touch with us. Members get monthly newsletters.

Immunodeficiency UK is reliant on voluntary donations. To make a donation, please go to [www.immunodeficiencyuk.org/donate](http://www.immunodeficiencyuk.org/donate)

Registered charity number 1193166. First edition May 2022.



Supporting families affected by primary and secondary immunodeficiency

## Taking control

# Taking control of your healthcare

[www.immunodeficiencyuk.org](http://www.immunodeficiencyuk.org)  
[hello@immunodeficiencyuk.org](mailto:hello@immunodeficiencyuk.org)  
0800 987 8986



Supporting families affected by primary and secondary immunodeficiency

## Introduction

Once you have been diagnosed with a significant condition it is important to feel in control of your healthcare. This is especially the case when you have a rare condition, such as certain types of immune deficiency, because some healthcare professionals may not be familiar with your condition.

This leaflet offers advice about taking control of your health and wellbeing.

## Learn as much as you can about your condition

Your specialist team might have given you lots of information, both verbal and written. Make sure you understand this and read through everything carefully. Don't be afraid to ask if there is something you don't understand. Use the internet wisely to find out more information from trusted sources; for example, the NHS and Immunodeficiency UK.

## Keep a folder of information related to your condition

In the folder, keep letters from your healthcare team, your medical records and any notes you make during GP and hospital appointments.

## Know how to contact your healthcare teams

Make sure that you have the phone numbers and email addresses for your specialist team and your GP. Know who to contact in the case of an emergency.

## Prepare for every appointment

Make notes of what you want to say at your appointment, so you don't forget anything. Consider taking a relative or friend for support if you think this would be helpful. Make notes during the consultation. Be honest and tell the full story, and don't be afraid to challenge your healthcare providers. Ask for further explanations if needed and ensure you are clear about the next steps in your care and treatment.

## Medical advice

Your clinical teams are experts. Once you are clear about the advice they have given you, make sure you follow it. Ask for a care plan and arrangements for follow-up.

Make a note on your calendar or set an alert on your phone of when you expect your next appointment to be, so that you can chase it up if it is overdue. If your healthcare team refer you for a scan or another medical procedure, enquire about the waiting time. That way, you can chase up the appointment if you don't hear anything within a reasonable time.

## Medication

Keep in your folder and/or your phone an up-to-date list of your medications and the doses. Having this list to hand will be useful when consulting a pharmacist about the appropriateness of over-the-counter medicines, if your healthcare team can't access your records for some reason, or if you run out of a medication while on holiday and need an emergency prescription.

It is always useful to know the reason why you have been prescribed a particular medication. The patient information leaflet that is enclosed with each medication will tell you what the drug is used for, or you can ask your pharmacist.

## Look after your overall health

Keep yourself in good health. Take advantage of screening tests and immunisations. Lead a healthy lifestyle by eating a balanced diet and exercising. Don't smoke and keep your alcohol intake within recommended limits. Visit the Drinkaware website for guidance at [www.drinkaware.co.uk](http://www.drinkaware.co.uk).

## Be persistent

Sometimes it is necessary to be persistent to ensure that you get the care and support you need. Be polite but resolute when ensuring your needs are met.

## Contact others with the same condition

Patient support groups can be a valuable resource and provide the opportunity for you to connect with others living with the same condition. There are Facebook groups where information and experiences can be exchanged. Please be aware, however, that sometimes information posted to these groups can be inaccurate. If you are in doubt about the credibility of reported facts or claims, please seek clarification from your healthcare team.

## Set goals

Set realistic lifestyle goals, recognise your achievements and celebrate your successes.