



HELP THE NHS HELP YOU

How do you navigate a hospital system that can feel labyrinthine and alienating? **Anna Studman** explains how to get referred to the right place, make the most of your hospital appointments and access the best care

You're finally at the hospital appointment you've waited months for. But before you know it, it's over, and you're left frustrated and confused. The doctor didn't seem to know your history, and you have unanswered questions about what's to come swirling around your head. When a follow-up letter arrives, it's full of jargon you don't understand.

It's easy to end up in the role of a passive patient when you enter the healthcare system. After all, you may not be a medical expert. But, for the best results, it pays to be an active partner in the process.

The NHS is a large and complex beast, with both time and resources under immense pressure. All too often, communication is not as joined-up as it should be, and it's easy for information to get lost along the way. In this environment, you are your own best advocate for your health. Here, we give you the right tools to navigate the system, and get the best out of your hospital experience.

You may not be proactively offered a choice of where to go for your referral, but you have the right to decide



1 / GETTING THE RIGHT REFERRAL

It all starts with describing your symptoms well to your GP. Dr John Paul Jeans says most of what informs a referral comes from the details you share at this stage.

If you're going to the GP with a referral in mind, try not to see them as a gatekeeper to hospital care. Focus on how you are feeling and what is wrong, rather than where you think you need to go next. Dr Kartik Modha points out that different symptoms have different referral pathways – so the suitability of the referral you get will really depend on how you describe them.

Dr Jeans has some tips for how to do this: 'Don't lead the doctor; describe how your body isn't working the way it should be – and be as specific as possible. Only use medical terms if you fully understand them – you don't want to give the wrong message.'

Dr Jeans says that the best referrals come from the patient outlining:

- what the problem is
- how long it's been going on
- what your primary concerns are.

Be honest and concise. For example: you have blood in your stool, it's been going on for a few days, and you're worried it might be colon cancer.

2 / CHOOSING YOUR HOSPITAL

Many patients don't know that they have the right to choose which hospital to be referred to. This choice may not be proactively offered to you – and will often just be your closest hospital – so you might have to ask.

Within the NHS, you can choose the hospital and even the specialist team, but not the specific doctor.

There are resources online that allow you to research the best hospital or specialist team within a field. The NHS provides a consultant search tool where you can find out how a consultant performs for a particular procedure and how many times they've done it.

Waiting times

Average waiting times vary depending on your condition, and from hospital to hospital. You can find average waiting times on the NHS Online waiting times guide or through the NHS e-Referral portal.

You have the right to switch hospitals if you're likely to be waiting longer than the maximum specified waiting time (in England, it's 18 weeks for non-urgent consultant-led treatments) – for example, if your appointment is cancelled and needs to be rescheduled.

Desperate to be seen sooner? One GP told us that you can try phoning the hospital as soon as you get your appointment letter and asking if they have any cancellations.

If your condition gets worse, go back to your GP to re-evaluate your options.

Our panel of experts



Trishna Bharadia
campaigner, public speaker and patient advocate



Dr Amir Hannan
GP and advocate of patient access to medical records



Dr John Paul Jeans
anaesthetist and intensive care registrar, Imperial College Healthcare Trust



Professor Dawn Langdon
professor of neuropsychology at Royal Holloway, University of London



Dr Kartik Modha
GP and founder of specialist recommendation portal myHealthSpecialist



Professor Martyn Partridge
professor of respiratory medicine at Imperial College London



Bernadette Porter MBE
consultant nurse; chief executive of digital care service, NeuroResponse



Dr Hugh Rayner
consultant nephrologist; developed plain English guidance for doctors



Deborah Wyatt
director of online health social network, talkhealth

3 / PREPARING FOR A HOSPITAL APPOINTMENT

Preparation is key to getting the best out of your appointment. The level and type of preparation you do will depend slightly on what you're being referred for, and whether it's a first appointment or a regular one for a chronic condition.

If you're a first-time patient, make use of your GP – they should be able to give an idea of what to expect, and questions

you can ask. Dr Modha advises people think about their expected outcomes. For example you may be looking for a diagnosis, a treatment plan, and/or a follow-up appointment.

Martyn Partridge, Professor of Respiratory Medicine, recommends you think about the following in preparation for a hospital appointment:

- A list of symptoms that you want the doctor to address.
- Any thoughts about what might have caused the situation or made it worse.
- Are you particularly concerned about a specific condition? If so, mention it. For example, the possibility of cancer, a sexually transmitted disease or something hereditary.
- Even though we all know about the perils of self-diagnosing over the internet, if you've done this and are worrying about something in particular, or have taken some online advice for treatment, tell the doctor.
- Prepare a list of any significant previous illnesses or operations you've had and rough dates. Forgetting to tell the doctor you had pneumonia as a child or that you once had a very bad reaction to aspirin may be extremely important pieces of information. Do not assume that the hospital doctor has access to all of your previous notes or that a GP referral letter will necessarily contain all the relevant information.
- Take a list of any medication you are currently on, as well as the dosage. If it's easier, you can take your repeat prescription paperwork, or the medication packets.

EXPERT VIEW

SHARED MEDICAL RECORDS BENEFIT PATIENTS AND DOCTORS

Dr Amir Hannan



Our practice in Manchester enables patients and carers to have

full access to their electronic health records, which allows them to better understand their healthcare needs – in partnership with the doctor.

All patients are encouraged to sign up so that they can see what the GP or practice nurse has written in the notes and see results of tests and letters back from the hospital as soon as they arrive in the surgery.

In control

Our experience is that responsibly sharing the records with our patients and carers allows them to feel more in control of their healthcare. This also leads to them feeling better prepared when they visit the hospital. They can even have up-to-date information on their smartphone, tablet or PC to share with hospital staff if this works for them – and it can make a medical history or symptom check much easier.



Taking charge of your medical records

Unfortunately, as the system currently stands, communication between healthcare providers is less joined-up than it should be.

There's no national system for NHS records. Each hospital trust has its own version of health records – and the trusts don't necessarily speak to each other.

Dawn Langdon, professor of neuropsychology at Royal Holloway University of London, explains that just because you've

told your doctor something, it doesn't mean your hospital team will know about it. She said it's the same if you've been to A&E or had tests at a different hospital or with your GP nurse – don't assume they'll know about this.

This means that the onus is on you to keep letters, test results, discharge notes, and details of medication in one place, to create a dossier of your health history. Patient advocate Trishna

Bharadia points out that this is a particular concern for patients with multiple conditions, who may have a struggle keeping track of the paperwork across different sites and specialisms.

Health charities such as the British Heart Foundation and Macmillan Cancer Support have resources for how to manage your condition, what questions to ask in appointments, and in between care.



4 / AT THE APPOINTMENT

When you arrive

When you arrive at the hospital and check in with the receptionist, you can ask how long the waiting time is, and who you will see in the clinic that day. The latter may be more meaningful to regular patients who want to know if they are going to be seen by a particular consultant.

Speaking to the specialist

Tell the hospital doctor what you told your GP about symptoms and also what you hope the outcome of the appointment will be. Be as clear, specific and concise as you can be.

The specialist should ask you what your main concerns are, and whether you've understood everything that's been discussed. But if they don't, do mention any concerns that you feel haven't been addressed and ask for clarification if you're unsure of anything that's been spoken about.

Try and think of your conversation as a two-way relationship between you and the specialist, says Ms Bharadia. Deborah Wyatt, founder of online health social network TalkHealth, says that patients are often afraid to be assertive. She argues that consultations should be a dialogue between you and your doctor rather than a monologue from the latter. It's up to both the patient and doctor to proactively foster this partnership – so that you can share in the

management of your own health and treatment plans.

Professor Langdon notes that the complexity of explaining the risks and benefits of different treatment options with statistics and studies can be a barrier to this, but it's something that needs to be tackled by healthcare professionals. For your part, if you feel bamboozled by options, speak up and ask the specialist to re-explain them, or ask where you can find out more.

The end of the appointment

To make sure you have what you need from your appointment, Professor Partridge says:

- Don't leave with unanswered questions. Scan the list of questions you brought with you and check you have the answers you need.
- Ask what arrangements are in place for follow up, whether you can alter these and whether a specialist nurse is available for advice in between appointments.
- Ask how and when you will receive any test results.
- Ask for specific details to be included in the hospital letter (see 'making sense of hospital letters, opposite).
- Ask the doctor if there are any websites they recommend. Many illness-specific health charities have online resources for patients; the NHS Apps Library has suggestions for apps to help manage specific conditions.



5 / NEXT STEPS

Follow-up questions

It's important to make sure you get as much information as you can during your appointment, because it can be difficult to get answers from your specialist in between appointments.

If you want to follow up, Dr Modha advises that your first port of call should be the specialist's secretary – you should have their number on a hospital letter. They may not always respond, in which case, he points to the Patient Advice Liaison Service (PALS). It will have a base in your local hospital, and can offer advice, support and information on health matters.

Ms Bharadia also highlights patient networks as a potentially helpful source of information. She says they can be good for finding out what to expect in terms of wait times, and processes – for example, when to call to follow up, how long results might usually take – but cautions against looking for medical advice.

Between appointments

If you have recurring appointments for a chronic illness, there are resources that can help you track and manage your condition in between visits.

Bernadette Porter has developed a digital resource, called Neuroresponse, for MS patients to access expert advice and care in between hospital appointments. She says the principles of this program can be applied further to other chronic conditions – the ability to track your symptoms, developing a care plan in partnership with your doctor, and supporting out-of-hospital treatments where appropriate, like with simple home tests.

Your GP or consultant, or a specific health charity, might be able to advise you of programs like this that are relevant to you. If nothing is available, keeping a symptom diary can be helpful so that you are well-prepared for your next appointment.

6 / MAKING SENSE OF HOSPITAL LETTERS

Hospital letters are usually sent out to you and your GP after a hospital appointment. They are vitally important in ensuring patients understand what's going on with their health, but a lot of the time they are packed with confusing and overly technical medical language that can alienate patients and reinforce a doctor-to-patient hierarchy.

Dr Hugh Rayner, a kidney specialist who has developed guidance for healthcare professionals on writing to patients in plain English, says that hospital letters should be:

- Addressed directly to the patient, instead of the GP.
- Informative and easy to read for a non-healthcare professional, replacing inaccessible technical terms with clear, descriptive language.
- Have a clear action plan at the end including next steps for treatment and the timings for results and follow-up appointments.

See 'Better letters' right, for some tips on what to expect from a medical letter. A complete change in how such letters are written will have to be led by healthcare professionals. But as a patient you can still make a difference. You're entitled to ask for plain English information directed at you to be in the letter. This should help avoid too much jargon.

Ask the specialist to outline the main things discussed in the appointment, what you need to know, plans for next steps and contact details for who to speak to if you need to follow up.

Better letters

Letters written to you in simple terms will be easier to understand, as the example below shows...

- **Bad:** 'He has persistent gross bilateral leg oedema, which is impairing his mobility. His compliance with treatment was suboptimal but has improved in the last fortnight.'
- **Good:** 'You still have a lot of swelling of the legs, which makes it hard for you to walk. You said you sometimes forgot to take your tablets in the past, but have taken them every day in the last two weeks.'



EXPERT VIEW

WRITING HOSPITAL LETTERS IN PLAIN ENGLISH

Dr Hugh Rayner



A good hospital letter makes a real difference and leads to

all sorts of benefits for the patient. Doctors are so used to the medical language they use that they can be blind to the disempowering effect it can have on a patient, stopping them from understanding and engaging in their own healthcare.

Using clearer language is a simple change that will have a great impact. It is something that has virtually no cost, and is widely supported by patients and by healthcare staff who have adopted it. And writing directly to the patient, rather than about the patient to the GP, has a big effect on communication more generally.

We need change in the medical profession, which can be slow to come by. But we can also galvanise patients to ask for better. You're entitled to request that any letters are written directly to you, as this is best practice recommended by the Academy of Medical Royal Colleges.

THE BOTTOM LINE

Navigating the hospital system can feel daunting and frustrating, and better access to medical records and use of plain English would help the patient experience. But there are things you can do as a patient to make sure you get better outcomes. Become an active participant in your healthcare: prepare questions for your appointment, be clear about what you expect, and have all your medical documentation to hand. If in doubt, ask for clarification, push for easy to understand hospital letters, and make use of online resources where available.

FIND OUT MORE

Recent articles in *Which?*

- 'Doctors prescribed a course of plain English', November 2018, p8
- 'Finding a way through the broken care system', February 2018, p18
- 'Help your GP to help you', September 2017, p18

Other useful contacts

- Find your local PALS (Patient Liaison and Advice Service) office: nhs.uk
- Find specialists recommended by doctors: myhealthspecialist.com
- Join an online community for health discussion, support and information: talkhealthpartnership.com