

Consultation checklist

Before you leave your hospital appointment, make sure you are happy with the information you've been given. Use the following checklist as a prompt for your questions:

- I would like to check that I understand what you said (then repeat back what the doctor has told you).
- Can you explain it again, please?
- Could I have a copy of any letters sent to other doctors?
- What are these tests for?
- How and when will I get the results?
- What do you think is the best course of treatment for me?
- Are there any side effects or risks?
- How long will I need the treatment for?
- How will I know if the treatment is working?
- How good is this treatment?
- Have you treated similar cases, and if so, what was the outcome?
- What will happen if I don't have any treatment?
- Are there other things I can do to help myself?
- What happens next?
- Should I come back and see you again, and if so, when?
- Who should I talk to if I am concerned/if things get worse?
- Are there leaflets about my condition/this procedure that I could read?

Remember to write down your doctor's and specialist nurse's name, and the email address and telephone number of the nurse and department's secretary. These may come in handy in the future.

About the CGD Society

The Chronic Granulomatous Disorder Society (CGD Society) is the leading global charity dedicated to promoting an understanding of CGD and providing support to affected individuals and their families.

Our website www.cgdsociety.org provides medical information and practical advice on living with CGD. It is free to become a member of the CGD Society. Please go to www.cgdsociety.org/register.

If we can be of any help, please contact us at hello@cgdsociety.org or on 0800 987 8988, where you can leave a message.

Our charity is reliant on voluntary donations. To make a donation, please go to www.cgdsociety.org/donate.



Making the most of your appointments

hello@cgdsociety.org
0800 987 8988
www.cgdsociety.org

This leaflet gives practical advice for taking the stress out of hospital appointments and making sure you get the full benefit from the important time you spend with your doctor and nursing team.

Be prepared

Whether you're meeting your doctor for the first time or you've seen them on many occasions previously, it's good to be prepared. Make notes in advance of your appointment that include:

- any medicines and pills you take, or bring them to the appointment with you
- any symptoms that concern you (aches, pains or feelings)
- when the symptoms started and what makes them better or worse.

Also take along the dates of any recent illness. You can ask your GP to print out a list of appointments and medicines you or your child has received.

If you require an interpreter or any other communication aid, speak to the hospital in advance of your appointment so that the necessary arrangements can be made.

Plan your journey to the hospital, building in extra time for parking if you're travelling by car. Arriving for your appointment with time to relax and gather your thoughts is worthwhile.

Write down your questions and concerns

Write a list of questions you would like to have answered, with the most important ones at the top. That way, if your appointment is short, you'll be sure to get your most pressing queries answered. Questions that remain unanswered could perhaps be emailed to your doctor or nurse, or left until your next appointment.

Take someone with you

Hospital appointments can cause stress and anxiety. Taking someone with you, such as a friend or relative, may help to relieve any nervous tension. They can offer emotional support, think objectively about what is being said, and listen and take notes while you ask questions. If you do ask a friend to accompany you, gently explain to them that unless the doctor directs any questions or requests opinions from them they are there for support only, because the doctor will want to spend time talking to you. It's your right to have someone accompany you, so don't be dissuaded by a doctor or anyone else.

Be on time and don't get stressed if the clinic is running late

If on arrival for your appointment you discover your doctor is running late, remember that the most likely reason is because someone else is getting the help they need. Take something to keep you occupied in case you have to wait to be seen, and try to keep calm. The receptionist should be able to give you an idea of the waiting time.

Stay positive

You may feel angry and frustrated at times, but it's vital to try to stay positive, especially when you're seeing the medical team. This doesn't mean you can't show your emotions or explain how difficult you're finding something, but focusing on being positive and removing extreme emotion from a situation may help you get what you need. As time goes by and you deal with more and more doctors, you'll get better and better at communicating with them. What you have to say about your condition and your thoughts about how to manage it are just as vital as what the medical team is doing.

Take notes during your appointment

Taking notes during your appointment will help you to recall what the doctor has told you. If you don't want to make written notes, record the appointment with your smartphone or get a family member or friend to write down the major points for you. This will enable you to review the appointment at your leisure once you're in your own (less stressful) environment. You also have the right to request a copy of the doctor's notes.

Ask for visual prompts

The appointment may involve being given explanations about something that's happening in the body or a procedure that's being planned. If you're having trouble visualising exactly what is being explained, ask your doctor to show you a picture or draw a diagram to help you understand what they mean. Ask them to write down the name of any complicated medical terms, too.

Ask how you can learn more

Ask your doctor if they can recommend a book, pamphlet or website (e.g. the CGD Society website: www.cgdsociety.org) about your condition or the treatment you are going to receive. The more understanding you have, the more effective you'll be in helping to treat and manage your or your child's condition.

Remember, if you believe you are not being dealt with properly, then you can complain. You can find further information on this at www.nhs.uk/choiceintheNHS/Rightsandpledges/complaints/Pages/NHScomplaints.aspx

Contact the CGD Clinical Nurse Specialist (CNS) before your appointment to share any concerns you have. Prior notice of your concerns will enable the CGD CNS to discuss them with the medical team before your visit and ensure they are addressed in clinic. Contact details of the CGD CNS are available here www.cgdsociety.org/services/ukbasednursingservices