

“Why Am I Discharged from Hospital Outpatients?”

A frequently asked question

Helen Stewart, Geneticist

I was very pleased to be invited to the EDS Christmas Party in Cheltenham in December. I met some of you and had some very interesting and stimulating discussions. Some of the discussions were about genetics but some were about the practical issues you face.

One issue arose relating to why you or your children are discharged by specialist doctors and how that makes you feel.

I am aware that many of you or your children have ongoing medical problems that may affect you to a greater or lesser extent though out your lives. I can understand that you may feel let down or dismissed if you are discharged. Some people have said they felt “abandoned” when they were discharged.

From a doctor’s perspective I hope I can explain some of the reasons why we might discharge you.

One reason may simply be that the particular problem for which you were referred has gone away. Another reason may be that treatment or monitoring has been recommended and the specialist recommends that the treatment or monitoring should continue under the care of your local hospital doctor or your GP. Sometimes we know that we cannot recommend any particular treatment or that we have taken investigations as far as we can at the present time.

Some specialities are under pressure to see more new patients than follow-up patients due to Government targets. In this case, if you need to be seen again, your GP may need to re-refer you.

Geneticists often see people one or more times when a diagnosis is made and may be able to do some genetic tests. We may see people around the time of pregnancies in order to offer advice and sometimes testing. When a child is diagnosed with a genetic condition, we may discharge that child and suggest that they seek genetic advice in their own right as a young adult, when they may have concerns about inheritance patterns. However, we are involved in ongoing management for some diseases.

Often we avoid seeing people in between these times as we all appreciate hospital appointments may involve travel, parking, time off work or school and may cause distress or anxiety. We also appreciate the number of hospital appointments you or your child may have and therefore try to help minimise this by avoiding appointments that may duplicate input provided by a different specialist.

Often being discharged is negotiable – we may discuss with a patient or family whether they feel comfortable about not having another appointment and will see them again if they still want to be seen.

If you are discharged, we are still available to answer questions or new concerns. Sometimes you may be given an ‘open appointment’ which means you do not need to go back through your GP or specialist to obtain an appointment: you merely contact us directly. We are also always available if a GP or local specialist needs to re-refer you.