

ASK US...

Q & A's with Alex & Jane

YOUR QUESTIONS FOR THE ALFRED HTC TEAM

I live in the country and am wondering what happens when I come to the Alfred Haemophilia Treatment centre?

When you come to The Alfred HTC you will meet a number of different people, all important for your care. You will be welcomed by Susan in the office, you will meet with the doctor, the social worker, the physio and the nurse, you may also meet the data manager and the psychologist. All of these people can help you. The Alfred HTC is the state-wide treatment centre for haemophilia and other inherited bleeding disorders, so we have many country patients. All patients are recorded on the ABDR, this helps whenever one of our patients needs any treatment, we will talk to you about the ABDR and ask for your consent to be on the ABDR.

Anyone living more than 100kms from the Melbourne CBD can claim reimbursement for travel costs when coming to an appointment and accommodation if they are required to stay overnight for any medically sanctioned reason. We encourage all regional patients to utilise The Victorian Patient Assisted Travel Scheme (VPTAS). It requires a claim form and the social workers can help with this. The forms are available on line or from social work. If you are attending other specialist appointments (a part from the HTC) at the Alfred, please ensure you have a separate VPTAS form signed off by the medical officer you are treated by.

If you need to stay in Melbourne, the Social Work team have a list of local hotels and places to stay. If you have any particular issues associated with transport or accommodation the social workers can assist with these too. Some country towns have a great community car system, and this is really helpful when you can't get yourself down to Melbourne.

For country patients we recommend

a visit to the local GP and may save a trip into Melbourne. The HTC is able to guide and inform the regional medical service depending on the nature of the medical issue. In some cases it may require the patient to be sent to Melbourne by road or air ambulance for further investigation and treatment or a supply of treatment can be sent urgently to the regional hospital to administer. If you are on regular prophylaxis, keeping your treatment records up to date on the ABDR will also help the HTC team monitor your health and alert them to any concerns.

Some regional patients, depending on their haemophilia status, are seen for yearly review and this appointment will be sent to you. We also like to give you a text reminder a few days before your appointment.

What is the transition process and how involved can parents be?

The transition process begins long before the young person has their first appointment at the Alfred Hospital. All through the treatment at the Royal Children's Hospital the team, including parents, teachers, nurses, doctors, physics, social workers, are helping the child to learn about their condition, become independent with their treatment, and prepare to shift to an adult treatment centre at the appropriate time. This transition usually happens after the young person finishes school, but there are many factors which influence this timing. Ideally, the young person will get to know some of the team from the adult centre, and also get to visit prior to their transfer of care. Several meetings are held between the RCH and Alfred HTC teams to discuss and hand over information.

The Royal Children's Hospital Haemophilia Treatment Centre team arrange a final review clinic where they will say a formal goodbye and to prepare the young person for the next stage in their treatment. A written

summary is arranged to be forwarded to the Alfred HTC. At this point an appointment is made for the young person to come to the Alfred. When possible we have a special clinic for transition, in which we allocate more time to get to know each new patient, and to talk about their needs.

Parents are encouraged and welcomed to transition clinic and we think it is supportive for the young person and helpful for the Haemophilia Treatment Centre team. However it is important for families to remember that the young person is now becoming an adult and will be seen by themselves, at least for part of the appointment. Often the way it works is that the doctor talks to the young person alone and then invites the parent/support person into the room after a while. This gives the opportunity for privacy and developing independence and also a chance for parent/support person to find out what is going on and ask any questions that they have. This can only happen with the consent of the young person.

The Social Workers (Jane and Alex) are always available to talk to parents and significant others about any concerns. Sometimes the process of growing up can put some distance between parents and their children, and we know that it is hard to watch from the sidelines after having put so much into looking after your child. Sometimes they will make bad decisions, but it is important to remember it is their decision to make. Likewise, it is difficult for some young people who are ready ahead of their parents and who want to manage their health care by themselves. Please let someone in the team know if this sounds like your situation. We will try and support you all as much as possible.

Jane Portnoy & Alex Coombs
Social Workers, Haemophilia & Other Inherited Disorders Team
ALFRED HEALTH

Please send your questions for the next edition to Jane, Alex or to the HFV team by the 1st May. You can remain anonymous, use an alias or just your first name. J.Portnoy@alfred.org.au, A.Coombs@alfred.org.au or julia@hfv.org.au