



A guide on moving from paediatric-to-adult healthcare.



**Information, tips and checklists for
young people and families.**



**Children
In Hospital**
Ireland (CIH)

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About Transition



What is Transition?

In health care, the term 'transition' is the word used to describe the process of transferring from child to adult health care services. Transition is not a single event. It should be seen as a gradual process of thinking, planning and preparing, which ensures that you and your parents are ready for the eventual move.

When will my transition start?

You and your parent(s)/guardian(s) should start thinking about the transition and move to adult health care services from around the age of 12. By doing this, you will have more time to prepare yourself for the transfer when it happens.

What will transition mean for me?

Transition means that you will be preparing to be looked after by a team who specialise in caring for adults with a long-term condition. Part of this preparation will include you becoming more involved in managing your health care and achieving more independence. You will need to find out all about your medical history and your condition. You will become more involved in looking after your medications, treatments, tests and procedures. Knowing how to keep well and manage your condition through attendance at clinic appointments, a good diet, exercise routines and other lifestyle choices is also part of the transition process.

What challenges could I expect during the transition process?

It is normal for any process involving change to have some challenges and transition is no different. The main challenges are:

- Moving from a setting that you are very familiar and comfortable with to a new setting that you know very little about.
- Getting to know people in the new healthcare team and their roles.
- Being more independent and learning to manage your condition.
- Starting to make decisions about your health care and your treatment.



Step 1. Thinking about Transition

(Up to 14 years approx*)

This stage is about introducing you and your parents to the idea of transition. During this time, you should start to learn more about your condition and begin to start taking a little more responsibility for your health care.

Top tips

- ✓ Try to learn more about your condition, medication and treatments.
- ✓ Think about questions you might like to ask at your hospital or clinic visits.
- ✓ Use your phone to set reminders about hospital appointments and taking your medication/treatments.
- ✓ It is worthwhile thinking about how exercise, diet and other lifestyle decisions affect your medical condition.
- ✓ Talk to your parents/guardians about your medical history – this will help when you are older and you have to answer your healthcare teams questions.



Why do I have to move to adult services, I am happy with my care now?

The staff in the children's services are experts in looking after the health care needs of younger children and teenagers. As you get older, your health care needs will change and the adult team will provide the care that is appropriate to your age. Transferring to adult health care services is a natural part of growing up, becoming more independent and taking more control of managing your condition.



Why do some people move at different ages?

The decision about the age at which a young person will transfer to adult health care services can depend on several things such as how healthy they are and hospital policy. The final decision on when you will transfer should be made together by you, your parent(s) /guardian(s) and the health care team.

FAQ



What does transition mean?

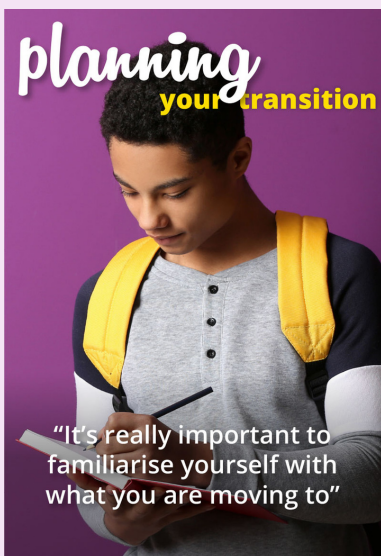
Transition is the word used to describe the process of moving from children to adult healthcare services. Transition should be a gradual process of planning and preparing giving you time to talk to your healthcare team about the eventual move.

Becoming Independent

Becoming more independent is a natural part of life and happens at different stages for different people. As you achieve more independence and understand your responsibilities, you should be included in decisions about your health care.

Here are some tips that other young people found useful:

- ✓ Be open and honest with your parents and health care team, this will build trust and help make your relationship with them better.
- ✓ Ask questions during your clinic visits.
- ✓ Set some small goals for you to achieve, for example, seeing the nurse or doctor alone for part of a clinic visit or contacting the pharmacy to organise your medication or treatment. These are small steps that will help you become more independent.
- ✓ Begin to take note of your clinic appointments and prepare yourself for them. You should note how you have been since your last visit and make a list of questions you may want to ask.
- ✓ Talk to your parents about your medical history and treatment. They will have plenty of knowledge about your health care that they can share with you. This may help you to feel more comfortable answering questions. Become more responsible for your own medication and/or treatment. Know what medication you take, when you take it and what it is for.
- ✓ Find out who you should contact in an emergency.



Step 2. Planning your Transition

(Up to 16 year approx*)

During this stage you should build on your existing knowledge about your condition. This will increase your confidence and help you when dealing with your health care team.

Top tips

- ✓ It is helpful to start taking more responsibility for your own medication and treatments. Know when and how much to take.
- ✓ It can seem daunting but you should begin to think about seeing your doctor or other health care professionals by yourself.
- ✓ Try to learn more about your condition and treatments and consider talking to others about them.
- ✓ It would be useful to start planning your move to adult health care. Ask your parents/guardians and your team about it – ask questions and express your concerns.
- ✓ Consider finding out the main differences between child and adult health care services – this way you will know what to expect when you move.
- ✓ Try to understand more about the impact of nutrition, exercise, alcohol and drugs on your overall health.

FAQ



When will I be moving?

Many young people move to the adult hospital/clinic between the ages of 16 and 18 years old but it can depend on your individual circumstances. Some young people wait until they have finished their leaving cert, for others, moving to other parts of the country for college can coincide with the move. You should talk with your parent(s)/guardian(s) and members of your health care team about when you can expect to make the move.



Do I have to change hospital?

You may have to change hospital as many of the adult services are often located in specialist hospitals. This could mean that the new hospital might be close to where you live or you may have to travel some distance to the new hospital. You should talk to your health care team about the hospital that they plan to transfer you to.



Can I choose which hospital/adult service I move to?

For many young people, the decision of where to move to is made by their consultant and can often be limited to hospitals within your catchment area. However, sometimes you may be able to choose which adult service that you will go to. You and your parent(s)/guardian(s) should try to find out which hospitals have clinics that look after young people with your condition and talk to your consultant about your preferences. Very often the decision may come down to location and what is practical for you.

Will the doctors in the children's hospital talk more to me about transition as it gets closer?

Your consultant and health care team should talk to you about transition but often this does not happen until you are very close to actually making the move. You and your parent(s)/guardian(s) should start asking your consultant and team about transition now so that you can begin to prepare.

Who is responsible for organising my transition?

The staff in the children's hospital are responsible for organising your transition. They will give you some information about the adult service that you will be moving to and should send a referral letter and/or relevant notes to the new clinic. Then you will have to wait for the staff in the adult service to contact you about your first visit. This process could differ depending on which children's hospital you attend, so you should speak to your team about their plans for your transition.

Will the new hospital have all my medical notes?

It is not usual for the children's hospital to transfer all your medical notes to the new adult services. It is more usual for a referral letter to be sent to the new clinic. This letter might also include a summary of the events that have occurred in the children's hospital and a copy of your surgeries, if relevant. In preparation for the transfer, you and your parent(s)/guardian(s) should write a brief medical history including the medications you are taking and the treatments you have had, along with any allergies you have.

Know about your medication and treatment

If you need to ask advice about your medication and/or medical tests or treatments, speak to your parent(s)/guardian(s) and health care professionals who will be more than happy to give you the information you need.

Your Medical History

- What surgeries/procedures, if any, have you had?
- When and where did the surgeries/procedures take place?
- Who carried out the surgeries/procedures?
- Have you had any allergic or adverse reaction to any medication/treatment?

Your Medication

- The name of the medication you take.
- Why you take the medication.
- The exact dosage that you need to take.
- Specific rules or instructions for the medication (for example, any particular storage instructions)
- Any side effects from the medication.
- The effects that could occur by mixing your medication with other medicine, drugs or alcohol.
- Which chemist you use.
- Which doctor/consultant prescribed the medication for you.

Your Tests or Treatments

- What medical tests have you had?
- What are the tests for?
- How often do you need to have the tests?
- Who carries out the tests?

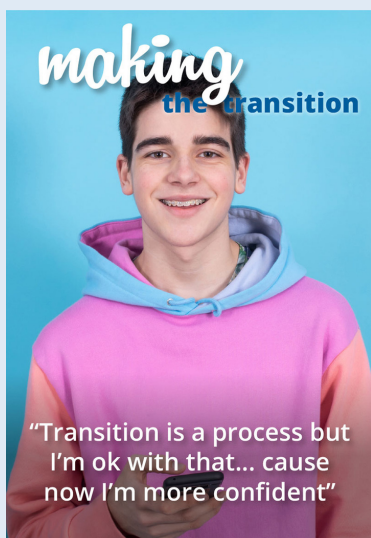


Questions to ask

The questions below are examples of the kinds of questions that you could ask. They are based on the questions that other young people said they wanted to ask before and after they made their transition

Use our 'Important Notes' section to write your own questions

- ? Why do I have to move to adult health care services
- ? Can I bring a parent/guardian or a friend with me for my first appointment
- ? When do you think I will be moving
- ? What will happen and who will I see on my first visit
- ? Which hospital/clinic will I be moving to
- ? Will I see the same health care staff at each visit
- ? Will the new hospital have all my medical notes
- ? What kind of waiting times can I expect at the adult clinic
- ? Who is responsible for organising my transition
- ? What medications and/or treatments are available in the adult clinic
- ? If I get ill before my first visit to the adult clinic, where should I go
- ? What are the hospital's/clinic's policies on home treatments
- ? Who will be my new consultant
- ? If I become an in-patient, how will that experience be different from the children's hospital
- ? Can I visit the new adult hospital/clinic before I have my first visit
- ? How long will I have to wait for my first visit
- ? Where is the clinic located in the hospital



Step 3. Making your Transition

(from 16 years approx *)

This stage is the final stage and involves the transfer to the appropriate adult health care service. At this stage you should be advised on when you are moving and where you will be moving to.

Top tips

- ✓ Find out which adult service you will be transferring to. Try to arrange to visit or make a phone call to the clinic before you move – this way you will find out what to expect at the first visit.
- ✓ As you get older, you will be expected to answer questions about your medical history, medication and treatments – try to find out as much as you can and maybe make some notes for yourself.
- ✓ Give some thought to your first visit to the adult clinic. Consider the questions you would like to ask and make a list to take with you.
- ✓ Continue to look after your medications and/or treatments – you will be better able to talk to your health care team by doing this.
- ✓ Think about your lifestyle choices (exercise, diet, hobbies, sport, education) –and the possible effects these could have on your condition. Aim to achieve a healthy match with your condition and lifestyle.
- ✓ If you can, start to contact your health care team yourself – arrange appointments, ask about medications and hospital visits.

FAQ



How do I get ready for the transfer?

Start preparing for your move by talking to your parent(s)/guardian(s) and your health care team. You could begin to get more involved in looking after your health care, for example, contacting the chemist about your prescriptions and making your own appointments. In this way, you are becoming more independent. If you know of other young people that have already moved to adult services, you could talk to them about their experiences. You could also listen to the 'transition stories' on this website and check out the various information sheets.



Does it feel strange when you first move to adult clinics?

The thought of moving to a new hospital and new clinic can be a little daunting for you and your parent(s)/guardian(s). From talking to young people who have already transferred to adult services, we know that preparing for the move is very important. Once you get used to the new surroundings and get to know your new team, you should settle into the new routine. Some young people look forward to the move, they want to be seen in a more adult environment and be spoken to directly.

? **Can I bring a parent/ guardian or friend with me for my first appointment in the adult clinic?**

Most young people are a little nervous about attending their first visit at the adult clinic, this is normal. The adult service sees you as being independent and responsible for managing your health. At the first visit, there can be a lot to take in so having a parent/guardian/friend can be helpful. If you want to bring someone along with you for support you can certainly do this. The health care team will more than likely address all their questions to you so be prepared to answer questions about your condition and experiences in the children's hospital/clinic. Remember, if you have someone with you but want to ask the medical team something personal; just ask the person to wait outside the room until you call them.

? **If I get ill before my first visit to the adult clinic, where should I go?**

If you become ill when you have been transferred to the adult services but are awaiting your first appointment, you should contact the staff at the children's services you previously attended, as they will have all your medical records and notes. The staff there would be the best people to help you in this situation.

? **Will I be with people my own age or will I be with older adults?**

Depending on your condition, you may find that when you visit the adult clinic there will be older people there too. Some hospitals run 'young people' clinics on a regular basis. Before you make the move, you should get in touch with the new adult clinic and find out if they have a clinic for young people.

? **Once I transfer to the adult services is it OK for me to get in touch with the children's service or hospital that I was attending?**

It can often be difficult to break the relationship with the team that you have been used to in the children's service. Your natural instinct might be to ring them if you have a query. However, once you move on to the adult service, it is important for you (and your parent(s)/guardian(s)) to discuss any worries or questions with your new health care team. You should be given information on how to contact your new adult healthcare team at your first adult clinic appointment.

Key differences in adult health care services

Your Responsibilities

- Give your opinion about your treatment plan.
- Keep note of your own appointments with the hospital/clinic.
- Look after your own medication schedule (what to take and when; how to order more and how/where to collect them.)
- Take some responsibility for organising other treatments or procedures that you may require.

Hospital/Environment

- There could be people of different ages, often much older around you at appointments or if you are admitted to hospital.
- Waiting times may sometimes be longer in adult services.
- You may not see the same team members at every clinic visit so you may have to repeat your medical history each time.
- You may spend less time with the doctor at your clinic visit.
- There may be different treatments and/or resources available in the adult clinic.

Communication

- Questions will more likely be directed to you and not your parent(s)/ guardian(s).
- You are still entitled to bring a family member or friend with you to hospital appointments; lots of adults take family members or friends along to important appointments for support.
- The key difference is that you will be the one to talk about your health and ask or answer questions.
- Health care staff may use more medical terms than you were used to in child services; don't be afraid to ask them to explain these to you.

Parent(s)/Guardian(s) Role

- Your parent(s)/ guardian(s) will continue to play a role in your health care but you will now have overall responsibility.
- If you are admitted to hospital your parent(s)/ guardian(s) will not be able to stay over with you

Talking to your healthcare team

Talking to your new healthcare team

You may know your team (such as, consultant, junior doctor, nurse specialist, technician, psychologist, dietician, physiotherapist) from the child services very well so it can seem a little scary moving and getting to know a new team. Just like getting to know anyone new, this will take a little time. Here is some advice from other young people who have already made the transition to adult services.

Ask questions!

- Sometimes health care professionals might use terms that you are not familiar with. If there is anything you do not understand don't be afraid to ask your doctor or other professional to explain it to you. It is their job to help you to understand everything.
- Write down your questions and bring them with you to your clinic visit.
- Use a notebook or your phone to jot down any important information and phone numbers that you might get from the team.
- If you like, bring someone (parent/guardian, family member or friend) with you for support and for an extra pair of ears (to remember what was said).
- If you have someone with you but want to ask the medical team something personal just ask the person to wait outside the room until you call them.
- Be open and honest and tell your team everything. You are an expert on your health so the more information you give them the better they can meet your needs.
- Remember that your health care team has heard or seen it all before.
- Find out who you should contact in case you have any unanswered questions.
- Your team are there to work on your health care with you, so trusting them and building a good relationship with them will be beneficial to both of you.
- If you are finding it difficult to talk to your health care team, don't suffer in silence, speak with a family member or someone you trust. They can speak up on your behalf at your next hospital or clinic appointment.

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The first visit to the adult clinic

The First Visit to the Adult Clinic/Hospital

Many young people feel a little nervous about their first visit to the adult clinic. This is quite normal considering they are used to attending the same hospital or clinic for many years. While all hospitals and clinics are different and will have procedures in place that work best for them, there are some things that will be the same. Whether you are feeling excited, nervous or a mix of the two, the following information might help you to be more prepared for your first visit.

What You Can Expect:

- Even though you will be meeting new people, the staff should help you to settle in.
- There may be other people in the clinic who are much older than you.
- Waiting times in the adult clinic can be longer than in the children's clinic.
- You may not see the full health care team on the first visit but will meet them at subsequent visits.
- The health care team would prefer to talk to you and not your parent(s)/guardian(s) so the questions they ask will be directed to you.

- At the first visit, there can be a lot to take in so having a parent/guardian/friend with you can be helpful. If you want to bring someone along with you for support you can certainly do this.
- Your consultation may be shorter than previous consultations in the children's clinic/hospital.
- Procedures may not be carried out in the order that you are used to.
- You may be asked to repeat your medical history and medication information to each person you see. This is normal as each health care professional wants to make sure that they know all about you and make their own notes.
- Most people get used to the new clinic and new team and most will build a good relationship with them over time.

How You Can Prepare:

- Find out the name of your new consultant and/or a specific nurse that you might be seeing at the clinic.
- Decide if you would like to bring someone with you for the first visit. Even if you do not want this person to see the nurse/doctor with you, they could be there for support and company while you wait. It is your choice.
- Learn about your medical condition and be able to answer questions. Talk to your parent(s) or guardian(s) and your medical team if you need their help.
- Bring a list of your medications and or treatments and your medical history with you.
- Know the name, address and contact details of the pharmacy you use for your medication or treatments, you could be asked for this information.
- Bring any record diaries that you keep (for example, your lung-function test or blood glucose readings).
- Make a list of questions so that you won't forget them on the day. For example, you might want to ask about the medications/treatments that are available in the adult clinic or you may want to know the procedures that will be carried out at each visit.
- Make sure to ask for details of who to contact in case of an emergency.
- If possible, make a trial run to the new hospital and find out where your clinic will be. This will mean that you won't have to worry about getting lost on the first day.
- If you can't do a trial run, make sure to leave plenty of time in advance of your appointment, so that you arrive early to find the clinic.
- When you see the health care team, talk to them and know that you can ask questions if you want to.
- You know best about your health and don't be afraid to speak up.



Transition Checklist

Read the statements below and tick the relevant box for each. This will highlight the areas you need to get some advice about. This will help you as you prepare for your transition. You should discuss any concerns with your parent(s)/guardian(s) and health care team.

Knowledge	Happy with this	Need some advice about this	Notes
I understand my medical condition	<input type="checkbox"/>	<input type="checkbox"/>	
I know about the tests that I need to have	<input type="checkbox"/>	<input type="checkbox"/>	
I know the names of my medications and what they do	<input type="checkbox"/>	<input type="checkbox"/>	
I know when and how to take my medication/treatments	<input type="checkbox"/>	<input type="checkbox"/>	
I am aware of my medical history (e.g. hospital visits, procedures, tests)	<input type="checkbox"/>	<input type="checkbox"/>	
I know the main differences between child and adult health care services	<input type="checkbox"/>	<input type="checkbox"/>	
I am happy to talk to the chemist about my medication/treatment	<input type="checkbox"/>	<input type="checkbox"/>	
I know how to care for my medical equipment (if applicable)	<input type="checkbox"/>	<input type="checkbox"/>	
I know who to call in an emergency	<input type="checkbox"/>	<input type="checkbox"/>	
Knowledge	Happy with this	Need some advice about this	Notes
I feel ready to prepare to be seen alone in the young person's/adult clinic	<input type="checkbox"/>	<input type="checkbox"/>	
I feel confident to ask my own questions in clinic	<input type="checkbox"/>	<input type="checkbox"/>	
I understand that I will have to take more responsibility for my health care as I get older	<input type="checkbox"/>	<input type="checkbox"/>	
I keep a record of my hospital/clinic appointments	<input type="checkbox"/>	<input type="checkbox"/>	

Health & Lifestyle	Happy with this	Need some advice about this	Notes
I am aware of the choices that I have to make in order to have a healthy lifestyle	<input type="checkbox"/>	<input type="checkbox"/>	
I know how much exercise is recommended for me	<input type="checkbox"/>	<input type="checkbox"/>	
I understand the risks of taking alcohol and drugs	<input type="checkbox"/>	<input type="checkbox"/>	
I know how important appropriate eating is for me	<input type="checkbox"/>	<input type="checkbox"/>	
I am aware that my medical condition may change as I get older	<input type="checkbox"/>	<input type="checkbox"/>	
I know where to get more information about my condition and other aspects of my life (e.g. sexual health, sport, education)	<input type="checkbox"/>	<input type="checkbox"/>	
About Transition	Happy with this	Need some advice about this	Notes
I understand the meaning of 'transition' and the reasons why I have to move to adult health services	<input type="checkbox"/>	<input type="checkbox"/>	
I understand about the transfer of my medical records/files to the adult health service	<input type="checkbox"/>	<input type="checkbox"/>	
I have found out about the challenges that I could expect during the transition process and feel ready to deal with them	<input type="checkbox"/>	<input type="checkbox"/>	



My Medical History

Patient Name:	Patient Hospital No.:	Date:
<input type="text"/>	<input type="text"/>	<input type="text"/>

My Current Medical History:

Current Medications:

Medication name	What is it taken for	How much do I take?	How often do I take it?

Allergies:

Medication name	What is it taken for	How much do I take?

Hospitalisation and/or surgery:

Date/Age	Procedure/Reason	Length of stay

My Local Doctor (GP):

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Address:

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Telephone:

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Useful Information

When planning for transition you should consider not only healthcare but also your wider physical, developmental, psychosocial, mental health, educational, lifestyle, cultural and financial needs. The following links provide useful youth focused information and resources related to these additional needs.

- General Information for Youth
- Disability and Illness Entitlements
- Further Education and Employment
- Mental Health
- LGBTI+
- Money and Finances



**Transition stage ages - Ages of transition used in this guide are approximate ages for preparing for making the transition to adult services. Actual age of transition may differ depending on condition, consultant and individual transition plan.*

Acknowledgements

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