Brighton and Sussex University Hospitals
NHS Trust

Brighton and Sussex University Hospitals

Transition to Adult Care policy

Version:	Version 1
Category and number:	C012
Approved by:	Clinical Policies Group
Date approved:	October 2020
Name of author:	Edwina Wooler, Paediatric Nurse Specialist
Name of responsible committee/individual:	Quality & Improvement Team
Name of responsible director:	Chief Nurse
Date issued:	September 2020
Review date:	October 2023
Target audience:	All Trust staff, including volunteers
Accessibility	Available on Trust intranet
Linked documents	Transitional Care for Teenagers and Young Adults with Diabetes at Royal Alexandra Children's Hospital, BSUH

Contents

1. **Introduction**

The importance of transitional care for all young people has been highlighted in the Children's National Service Framework (NSF) Hospital Standards [DH.2003] and the Royal College of Nursing (2013) with a requirement for children and adult services to acknowledge the needs of this group of patients when planning and developing services.
The Trust endorse the need for planned transitional services for young people in collaboration with colleagues in adult services and the wider health care community.

This policy sets out the Trust's expectations and provides practical guidance to ensure a structured and coordinated transition to adult health care services for all children and young people at the Royal Alexandra Children's Hospital.
The Trust is committed to improving this experience for all children and young people at the Alex, and for their parents and carers.
This policy outlines generic principles of transition and each speciality will have disease specific best practice pathways which will need to be taken into consideration.
This policy sets out the standards expected by the Trust in relation to effectively preparing children and young people for transition to adult care.

This guideline applies to:

- All clinical staff in all specialities caring for children and young people within the Trust.

- All children from age 11 years with a long term condition until they are successfully transferred to adult services. The age of transfer is largely dependent on the progress made by each young person and, where appropriate the caregiver and may be dependant to the young person's cognitive development rather than simply based on age.

2. Purpose

Transition is an essential component of high quality health-care for young people. It can be defined as "a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child centred to adult oriented health care systems". DH (2006)

The period of transition is a process where a young person's health and social needs should be regularly reviewed and assessed. To get transition right, services need to consider whether the rest of the care is developmentally appropriate. CQC (2014)

3. Definitions

More children with long-term conditions now live into adulthood. There is a growing need for Specialised Care and services to ensure seamless transition of young people to adult health care services. This is achieved by maintaining good liaison between Paediatrician, Adult Physician, GP and Allied Health Professionals. Inadequate transitional care impacts on long-term health outcomes for children and young people.

Self-management of any illness is often difficult and complex, particularly so during adolescence. This is due in part to pubertal changes, but also due to psychosocial changes such as erratic eating and exercise patterns, poor adherence to medication regimes, risk taking/antisocial behaviours, family stressors, psychological and self-image problems, frequently missed appointments, as well as binge drinking, smoking and eating disorders in a small minority.

Transition to adult services can be a traumatic period for young people, who commonly fall between services (McDonagh and Viner 2006). In some cases there is a risk of non-concordance and morbidity associated with this transition. These are frequently described (Viner 1999) and commonly reported clinical experiences. There is a perception of a lack of appreciation of young people's needs and issues, the worry that they will not receive adequate information, the fear about leaving their familiar health care team for an unknown medical provider, and the desire for autonomy and involvement in decision-making (McDonagh2005).
Concerns may be raised with the Child or Adult Safeguarding Teams where young people 'disappear' during transition and this will need to be monitored by individual teams to which the young people have been referred.

The aims of the transition are to:

1. Provide co-ordinated, uninterrupted health-care that is age-appropriate, developmentally appropriate and comprehensive with respect to all persons involved;
2. Promote skills in communication, decision-making, assertiveness, self-care, self-determination and self-advocacy;
3. Enhance the young person's sense of control and move towards independence.
4. Provide support for the parent(s)/guardian(s) of the young person during this process

5. Maximise lifelong functioning and potential

4. Responsibilities, Accountabilities and Duties

The Director of Nursing: Has responsibility for ensuring that appropriate processes are in place for the transition of young people (11-19yrs) from child-centred to adult orientated care.

The Head of Nursing Children's Services: Has responsibility for taking action on any non-compliance from the identified measurement tools that monitor compliance against this guidance.

The Safety and Quality committee: Has responsibility to ensure standards are met, actions are carried out and areas of concern are raised and escalated appropriately.

5. Policy

Transition in health care is one part of the wider transition from dependent child to independent adult. A transition program is an essential part of quality care for young people with chronic illness.

Transition is an active process rather than a single event. The process should begin early, be planned and regularly reviewed and be age and developmentally appropriate whenever possible.

A "sequential model" of transition is advocated (Forbes et al 2004). Such a model recognises that a young person's needs are changing and allows them to rehearse and prepare for adult based care.

The age of transfer should depend on the individual's physical and cognitive development, emotional maturity and state of health. Flexibility is key.

Transition services must also address the needs of the parent/guardian(s) whose role is evolving at this time in their son/daughters life and health-care.

In moving from child-centred to adult health services, young people undergo a change that is cultural as well as clinical.

A multidisciplinary approach is most effective and involves the whole multi-disciplinary team at RACH, the adult providers and general practice. Appropriate training needs should be identified to ensure all health care professionals have adequate skills particularly around communication with young people.

Service development must be undertaken in collaboration with the young people involved, enhancing their sense of control and independence in their healthcare. Coordination of transitional care is critical. A named professional should be identified for each young person to oversee his or her transition who links with a counterpart within the adult service to ensure seamless transition. It is acknowledged that in some cases services available in paediatric care are not mirrored in adult services. Transition services must undergo continued evaluation. This will be the responsibility of each individual specialty in liaison with colleagues in adult services who must show commitment to the transition process.

Our aim as a provider is to empower the young person and their parents/carers. This is achieved by using the Ready Steady Go programme developed by University Hospital Southampton to equip the young person with the necessary skills and knowledge to manage their healthcare confidently and successfully in both paediatric and adult services. Clearly this will include ensuring they are aware of basic information such as days and time of clinics, location of resources, clinics, laboratories, wards, car parking and refreshments.
Young people formally move from Children's Services to Adult Services by 19 years of age.

The steps in transition are:

1) Young people and their carers start the Ready Steady Go transition programme at around 11 years of age, if developmentally appropriate.
Young people and carers are introduced to Ready Steady Go through the 'Transition: moving into adult care' information leaflet and patient and carer information video at www.uhs.nhs.uk/readysteadygo.
2) At the next consultation the young person completes a 'Getting Ready' questionnaire which, through a series of structured questions, is designed to establish what needs to be done for a successful move to adult services. The issues are addressed over the following 1- 2 years and not in a single consultation.
3) In due course the young person completes the 'Steady' questionnaire which covers the topics in greater depth and is used to confirm progress and address any on-going issues or concerns.
4) Finally a 'Go' questionnaire is completed to ensure that the young person has all the skills and knowledge in place to "Go" to adult services.
5) The young person should be introduced to the adult team – ideally at least a year prior to transfer.
6) The carer completes a separate questionnaire which follows the same format as the Ready Steady Go questionnaires, alongside the young person to ensure that they are also supported through the transition process.
The actual timing of the move to adult services is one that is mutually agreed by the YP, parents or carers and medical professionals.

7) Any issues /concerns and progress are documented in the transition plan by the healthcare team/keyworker.
8) On transfer to adult services they should commence the “Hello to Adult Services” programme and a ‘Hello’ questionnaire be completed
Periodically the Hello questionnaire should be re-used to ensure they maintain knowledge and skill levels and that any new or on-going concerns or problems are addressed.
Those young people or adults whose first presentation with a long term condition is in adult services should be started on the ‘Hello to Adult Services’ programme - this follows the same format as Ready Steady Go. It can be used for all young people and adults regardless of age or sub-specialty.
9) Where the young person has learning difficulties the carer works through the Ready Steady Go programme with the young person engaging as much as possible. Carers with a severely disabled young person also start Ready Steady Go so that they too are prepared for the move to adult services; the programme allowing all concerns/issues to be carefully addressed and progress monitored prior to transfer.

6. Training Implications

Information on this policy will be provided to all new and existing Trust staff working in this field.

7. Monitoring Arrangements

It is important that we get things right for the patients, therefore monitoring of our approach will occur 3 yearly. To ensure we are complying with transition care plans we will review 25 sets of notes. Results will be reported back to the Head of Nursing.

If resources allow, young people’s experiences of the whole transfer process should be evaluated on alternate years using a satisfaction survey. This will be done jointly by both the Paediatric and Adult Teams. Recommendations for any changes in practice will be implemented as necessary.

8. Due Regard Assessment Screening

BSUH NHS Trust has a statutory duty to assess and consult on whether planning, policies and processes impact service users, staff and other stakeholders with regard to age, disability, gender (sex), gender identity, marriage or civil partnership, pregnancy and maternity, race (ethnicity, nationality, colour), religion or belief and sexual orientation. It recognises that some people may face multiple discrimination based on their identity. A review of the assessed impact of this policy against these criteria can be seen (Appendix 1).

9. Links to other Trust policies

Transitional Care for Teenagers and Young Adults with Diabetes at Royal Alexandra Children's Hospital, BSUH

10. Associated documentation

Aiming high for disabled children: delivering improved health services (NHS confederation 2009)
Independence: well-being and choice (DOH 2005)
Bridging the Gap: health care for adolescents (RCPCH 2003)
Care quality commission core standards
National Service Framework: children, young people and maternity services (DH, 2004)
RCN Adolescent Transition Care: Guidance for nursing staff (RCN, 2004)
Transition: Getting it right for young people (DH, 2006)
A transition guide for all services: key information for professionals about the transition process for disabled young people (DH, 2007)
0-18 years: guidance for all doctors (GMC, 2007)
Transition: Moving on well (DH, 2008)
You're Welcome Quality Criteria (DH, 2011)
Don't let me down: Ensuring a good transition for young people with palliative care needs (Marie Curie Cancer Care, 2012)
From the Pond into the Sea (CQC, 2015)

11. References

Blum RW, Garell D, Hodgman CH et al (1993) transition from child centred care to adult healthcare systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. Journal of Adolescent Health, 1993: pp 570-6
Department of Health (2003) Getting the right start: the National Service framework for children, young people and maternity services. Part 1: Standard for hospital services.
McDonagh JE, Kelly DA (2003) Transitioning care of the paediatric recipient to adult care givers. Ped Clin N Am 50 1561-1584
McDonagh JE (2005a) Growing up and moving on. Transition from paediatric to adult care. Paediatric Transplantation 9: 364-72
NICE (2004) Type 1 Diabetes: Diagnosis and management of Type 1 Diabetes in children. https://www.nice.org.uk/guidance/cg15 accessed on August 6th, 2015
Royal College of Nursing (2013) Adolescent transition care: Guidance for Nursing Staff, London: RCN

Viner R. (1999) Transition from Paediatric to Adult care. Bridging the gaps or passing the buck. http://adc.bmj.com/ published by group.bmj.com Accessed on August 6th 2015
National Association for the Welfare of Children in Hospital (1990). Setting Standards for Adolescents in Hospital (Quality Review Series). London: NAWCH.
S Burr. (1999). Children first. UNICEF UK committee initiative. Nursing Management. 6 (4), 18-23.
Department of Health (1996). The Patients Charter: Services for Children and Young People. London: HMSO.
Viner & Keane (1998). Youth Matters. Caring for Children in the Health Services. London: Action for Sick Children.
Royal College of Nursing (2004). 1. Adolescent Transitional Care Guidance for Nursing Staff. London: RCN.
Department of Health (2006). Transitions: Getting it right for young people. London: HMSO.
Department of Health (2004). National Service Framework for children, young people and maternity services: Core standards. London: HMSO.
Thornes, R (1991). Just for the Day. London: NAWCH.
Lewis, I (2012). Report of the Children's and young Peoples Outcome Forum. London: Department of Health.
Department of Health (2007). Your Welcome criteria. London: NHSE.
Bridging the gap: an integrated paediatric to adult clinical service for young adults with kidney failure', BMJ 2012; 344:e3718
NHS Confederation (2012). Children and young people's health-Shaping the future and improving outcomes. London: NHS confederation.
Royal College of Nursing (2008). Adolescent Boundaries and Connections. London: RCN.
Department of Health (2008). Transition - Moving on Well. LONDON: NHSE.

12. Appendices

Appendix 1 – Due Regard Assessment Tool

Appendix 2. - Transitional Care Plan. This document is a checklist to ensure the patient has all the skills necessary for a successful transfer to adult services.

Appendix 3. - Patient information leaflet on transition. This describes the transitional care process.

Appendix 4. - Patient and parent/carer questionnaires. This is the key tool for identifying the extent the patient is ready for transition to adult services and which skill sets/knowledge base require further development before successful transfer to adult services can be undertaken. (See appendices 3 -5)

Appendix 5. - Flow chart on how to use the Ready Steady Go programme

Appendix 1. - Key worker document. This document supports the key worker by providing additional guidance on how to assess the young person at each stage.

Appendix 1 Due Regard Assessment Tool

		Yes/No	Comments
1.	**Does the document/guidance affect one group less or more favourably than another on the basis of:**		
	• Age	Yes	As this is a policy for young people moving into adult care it will be aimed at those aged 11 to 18 years.
	• Disability	No	
	• Gender	No	
	• Gender identity	No	
	• Marriage and civil partnership	N/A	
	• Pregnancy and maternity	No	
	• Race	No	
	• Religion or belief	No	
	• Sexual orientation, including lesbian, gay and bisexual people	No	
2.	**Is there any evidence that some groups are affected differently and what is/are the evidence source(s)?**	Yes	Young people where English is not the first language may need an interpreter to guide them through the paperwork. Those with literacy issues would need an advocate to work with them.
3.	**If you have identified potential discrimination, are there any exceptions valid, legal and/or justifiable?**	No	
4.	**Is the impact of the document/guidance likely to be negative?**	No	
5.	**If so, can the impact be avoided?**	N/A	
6.	**What alternative is there to achieving the document/guidance without the impact?**	N/A	
7.	**Can we reduce the impact by taking different action and, if not, what, if any, are the reasons why the policy should continue in its current form?**	N/A	

8.	**Has the policy/guidance been assessed in terms of Human Rights to ensure service users, carers and staff are treated in line with the FREDA principles (fairness, respect, equality, dignity and autonomy)**	No	

If you have identified a potential discriminatory impact of this policy, please refer it to the Paediatric Nurse Specialists together with any suggestions as to the action required to avoid/reduce this impact.

For advice in respect of answering the above questions, please contact the Equality Team.

This is only a start

This leaflet is designed to get you to start thinking about adult services and the transition process.

For every person, this process will be slightly different but your healthcare team should be able to provide you and your family with information about it.

By talking about transition early, you should have plenty of time for discussions and questions, ensuring that you are fully prepared when the time comes to make the move to adult services.

Ask your healthcare team about the **Ready Steady Go** programme

You may like to use this section to jot down any questions you have about your transition.

My key worker is:

Contact details:

v2.0 2015

NHS

Transition: moving into adult care

Information for young people and families

What is transition?

In healthcare, we use the word "transition" to describe the process of preparing, planning and moving from children's to adult services.

Transition is a gradual process that gives you, and everyone involved in your care, time to get you ready to move to adult services and discuss what healthcare needs you will require as an adult.

This includes deciding which services are best for you and where you will receive that care.

Transition is about making plans with you - and not about you.

We understand that moving away from a team of doctors and nurses that you have been with for many years can be scary but hopefully, by getting involved in the transition process, you will feel more confident and happier about the move.

Why do I have to move?

As you get older, you will find that some of the things you want to discuss or some of the care you might need is not properly provided by our children's services.

Adult services are used to dealing with all sorts of issues that may arise, such as higher education, travelling, careers and sex.

You may also find that you would prefer to be seen in a more grown-up environment, rather than the usual children's departments or wards.

When do I have to move?

There is no exact time that is right for everyone.

The purpose of this leaflet is to get you thinking about moving on and preparing for it.

Your doctors and nurses may have an idea about when they feel that you might be ready but it is important that you are involved in that decision.

Can I choose where I move to?

Part of the transition process should be helping you to look at where your ongoing healthcare needs can best be met and how this will fit in with your future plans.

Your consultant or family doctor (GP) will be able to give you information to help you make the best decision.

If there is a choice of places, it is a good idea to visit all of them and then decide which is best for you.

Who can help me get ready?

Your healthcare team will be able to give you information and support about moving on.

They can help you get ready for adult services by:

- Teaching you about your condition or illness, its treatment and any possible side effects
- When you are ready, seeing you on your own for part of the clinic appointment and working towards seeing you on your own for the whole clinic appointment
- Making sure you know when to get help and who to contact in an emergency
- Helping you understand how your condition or illness might affect your future education and career plans
- Making sure you know about the support networks available
- Making sure you understand the importance of a healthy lifestyle, including exercise, diet, smoking and sex.

Your family

Your parents or carers have been really important in looking after your health and will be able to give you lots of helpful advice.

While you are in the process of transitioning, your parents will still be very involved in your care and their role is still important.

Try to talk to them and your health care team about how you feel about moving on to adult care and any questions or concerns you might have.

Also try to discuss practical issues relating to your health, such as getting to appointments, obtaining repeat prescriptions and asking questions in clinic.

While transition is all about you, it is important to realise that your parents may also be finding the process difficult as now they are handing over the responsibility to you.

This can be hard for many parents and they may have worries of their own.

You may find talking to them about your feelings, and allowing them a chance to tell you how they feel, will help you all through the process.

Questions you may like to discuss with your healthcare team:

- What is the plan for my transition?
- When am I moving to adult services?
- Can I choose which adult service I move to?
- What is different about the adult service?
- Can I meet the adult staff before I leave children's services?
- Can I visit the adult service to look around?
- Are there any young people I can talk to about moving to adult services?
- What do I need to know before I move to the adult service?
- When can I start getting more involved in my health care?
- How will my condition affect my future, such as my education and employment prospects?

DATE	SECTION NUMBER	PROGRESS NOTES/GOALS

Transition programme

NOTES

NHS

Transition programme

Ready Steady Go programme

Name: Hospital no:

Address: DOB:

Transition start date:

School/college:

Home tel no:

Email: Mobile no:

Diagnosis:

Target date for transfer adult services:

Discharge summary completed:

Resources: Date:

Transition leaflet for young people

Transition leaflet for parents/carers

Other (please specify)

Offer copy of clinic letters Date:

MDT involvement

Youth worker

Social worker

Psychology

Specialist nurse

Dietitian

Other

Key worker

Adult unit team contacts

Date of planned visit to adult unit

Transition programme

(K) KNOWLEDGE

		R	S	G
1.	Describes condition, effects and prognosis	☐	☐	☐
2.	Understands medication purpose and effects	☐	☐	☐
3.	Understands treatment purposes and effects	☐	☐	☐
4.	Knows key team members and their roles	☐	☐	☐

(S) SELF ADVOCACY

1.	Part/whole clinic appointment on their own	☐	☐	☐
2.	Knows how to make appointments/alter appointments	☐	☐	☐
3.	Understanding of confidentiality	☐	☐	☐
4.	Orders repeat prescriptions	☐	☐	☐
5.	Takes some/complete responsibility for medication/other treatment	☐	☐	☐
6.	Knows where to get help	☐	☐	☐

(H) HEALTH AND LIFESTYLE

1.	Understands importance of diet/exercise/dental care	☐	☐	☐
2.	Understands impact of smoking/alcohol/substance use	☐	☐	☐
3.	Understands sexual health issues/pregnancy/STDs	☐	☐	☐

(A) ACTIVITIES OF DAILY LIVING

1.	Self care/meal preparation	☐	☐	☐
2.	Independent travel/mobility	☐	☐	☐
3.	Trips/overnight stays away from home	☐	☐	☐
4.	Benefits	☐	☐	☐

Transition programme

(V) VOCATIONAL

		R	S	G
1.	Current and future education/impact of condition on career plans	☐	☐	☐
2.	School attendance and performance	☐	☐	☐
3.	Work experience and how to access careers advice	☐	☐	☐
4.	Outside activities and interests	☐	☐	☐
5.	Disclosure to school/employer	☐	☐	☐

(P) PSYCHOSOCIAL

1.	Self esteem/self confidence	☐	☐	☐
2.	Body/self image	☐	☐	☐
3.	Peer relationships/bullying	☐	☐	☐
4.	Support networks/family/disclosure to friends	☐	☐	☐
5.	Coping strategies	☐	☐	☐

(T) TRANSITION

1.	Understands concept of transition	☐	☐	☐
2.	Agrees transition plan	☐	☐	☐
3.	Attends transition clinic	☐	☐	☐
4.	Visits adult unit (if appropriate)	☐	☐	☐
5.	Sees GP independently	☐	☐	☐

Ready Date _____ Signature _____

Steady Date _____ Signature _____

Go Date _____ Signature _____

Transition programme

Please tick and date when addressed, details to be recorded in free text section giving code eg K2, A3

DATE	SECTION NUMBER	PROGRESS NOTES/GOALS

Parent/carer's transition programme

Name of parent:

Name of patient:

Date: Review (1) Review (2) Review (3)

Internet access: YES/NO

This transition plan is designed to help parents and carers feel confident about their knowledge and skills during the period of transition. Over the next few years we aim to equip your son/daughter and you with the necessary skills to manage their condition and hopefully increase your confidence and that of your son/daughter to transfer to adult services

.

Knowledge and skills	Yes	No	N/A
I understand the meaning of transition	☐	☐	☐
I know who's in the team and their respective roles	☐	☐	☐
I know about resources that offer support for parents/carers of young people with my son/daughter's condition.	☐	☐	☐
I understand what is likely to happen in the future regarding my son/daughter's condition.	☐	☐	☐
I understand the changes (physical and emotional) which occur during adolescence and how their condition potentially affects and is affected by this development.	☐	☐	☐
I am confident my son/daughter is knowledgeable about their condition and its therapy.	☐	☐	☐
I encourage my child to regularly exercise. I am aware of any restrictions my son/daughter may have.	☐	☐	☐
I feel confident in teaching my son/daughter to become responsible for their own medication at home.	☐	☐	☐

Parent/carers transition programme

Encouraging independence

	Yes	No	N/A
Is your son/daughter independent at home - dressing, bathing, preparing meals, doing chores, etc?	☐	☐	☐
I feel confident for my son/daughter to be seen on their own in clinic for part or all of clinic visits	☐	☐	☐
I understand my son/daughter's rights to information, privacy and confidentiality	☐	☐	☐
I know how to advise my son/daughter about financial help and other support	☐	☐	☐

Healthy lifestyle

I understand the importance of an appropriate healthy diet for young people	☐	☐	☐
I understand the effect of smoking, drugs and/or alcohol on my son/daughter's condition and general health	☐	☐	☐
I know where to access reliable sexual health information for young people and their parents	☐	☐	☐

Preparation for adult services

I feel confident in teaching my son/daughter how to contact the hospital themselves and to organise their repeat prescriptions	☐	☐	☐
I understand the differences between paediatric and adult medical care	☐	☐	☐
I know the plan for my son/daughter's medical care when he/she is an adult	☐	☐	☐

Please list any other things you have concerns about or would like extra help/advice with:

Thank you

The Ready Steady Go materials were developed by the Transition Steering Group led by Dr Arvind Nagra, paediatric nephrologist and clinical lead for transitional care at Southampton Children's Hospital, University Hospital Southampton NHS Foundation Trust based on the work of: 1. S Whitehouse and MC Paone. Bridging the gap from youth to adulthood. Contemporary Pediatrics; 1998, December. 13-16. 2. Paone MC, Wigle M, Saewyc E. The ON TRAC model for transitional care of adolescents. Prog Transplant 2006;16:291-302 3. Janet E McDonagh et al, J Child Health Care 2006;10(1):22-42. Users are permitted to use 'Ready Steady Go' and 'Hello to adult services' materials in their original format purely for non-commercial purposes. No modifications or changes of any kind are allowed without permission of University Hospital Southampton NHS Foundation Trust.

The following acknowledgement statement must be included in all publications which make reference to the use of these materials: "Ready Steady Go' and 'Hello to adult services' developed by the Transition Steering Group led by Dr Arvind Nagra, paediatric nephrologist and clinical lead for transitional care at Southampton Children's Hospital, University Hospital Southampton NHS Foundation Trust based on the work of: 1. S Whitehouse and MC Paone. Bridging the gap from youth to adulthood. Contemporary Pediatrics; 1998, December. 13-16. 2. Paone MC, Wigle M, Saewyc E. The ON TRAC model for transitional care of adolescents. Prog Transplant 2006;16:291-302 3. Janet E McDonagh et al, J Child Health Care 2006;10(1):22-42." Further information can be found at www.uhs.nhs.uk/readysteadygo v2.0 2015

The Ready Steady Go transition programme - Getting Ready

The medical and nursing team aim to support you as you get older and help you gradually develop the confidence and skills to take charge of your own healthcare.

Filling in this questionnaire will help the team create a programme to suit you.
Please answer all questions that are relevant to you and ask if you are unsure.

Name: Date:

Knowledge and skills	Yes	I would like some extra advice/help with this	Comment
KNOWLEDGE			
I can describe my condition			
I know when to take my medications, names, doses, how often, etc			
I know who's who in the medical and nursing team			
I understand the differences between children's and adult health care			
I know about resources that offer support for young people with my condition			
SELF ADVOCACY (speaking up for yourself)			
I feel ready to start preparing to be seen alone for part of the clinic visit in the future			
I ask my own questions in clinic			
I have heard and know about 'Ask 3 Questions'			
HEALTH AND LIFESTYLE			
I understand it is important to exercise for my general health and condition			
I understand the risks of alcohol, drugs and smoking to my health			
I understand what appropriate eating means for my general health			
I am aware that my condition can affect how I develop e.g. puberty			
I know where and how I can access reliable information about sexual health			

The Ready Steady Go transition programme - Getting Ready

Knowledge and skills	Yes	I would like some extra advice/help with this	Comment
DAILY LIVING			
I can look after myself at home in terms of dressing and bathing/showering etc			
I can make my own snacks/meals			
I am able to be away from home overnight			
SCHOOL AND YOUR FUTURE			
I am managing at school e.g. getting to and around school, school work, PE, friends, etc			
I know what I want to do when I leave school			
LEISURE			
I can use public transport and access my local community, e.g. shops, leisure centre, cinema			
I see my friends outside school			
MANAGING YOUR EMOTIONS			
I know how to deal with unwelcome comments/ bullying			
I know someone I can talk to when I feel sad/ fed-up			
I know how to deal with emotions such as anger or anxiety			
I am comfortable with the way I look			
I am happy with life			
TRANSFER TO ADULT CARE			
I understand the meaning of 'transition' and transfer of information about me			

Please list anything else you would like help or advice with:

Thank you

The Ready Steady Go materials were developed by the Transition Steering Group led by Dr Arvind Nagra, paediatric nephrologist and clinical lead for transitional care at Southampton Children's Hospital, University Hospital Southampton NHS Foundation Trust based on the work of: 1. S Whitehouse and MC Paone. Bridging the gap from youth to adulthood. Contemporary Pediatrics; 1998, December. 13-16. 2. Paone MC, Wigle M, Saewyc E. The ON TRAC model for transitional care of adolescents. Prog Transplant 2006;16:291-302 3. Janet E McDonagh et al, J Child Health Care 2006;10(1):22-42. Users are permitted to use 'Ready Steady Go' and 'Hello to adult services' materials in their original format purely for non-commercial purposes. No modifications or changes of any kind are allowed without permission of University Hospital Southampton NHS Foundation Trust.

The following acknowledgement statement must be included in all publications which make reference to the use of these materials: "Ready Steady Go' and 'Hello to adult services' developed by the Transition Steering Group led by Dr Arvind Nagra, paediatric nephrologist and clinical lead for transitional care at Southampton Children's Hospital, University Hospital Southampton NHS Foundation Trust based on the work of: 1. S Whitehouse and MC Paone. Bridging the gap from youth to adulthood. Contemporary Pediatrics; 1998, December. 13-16. 2. Paone MC, Wigle M, Saewyc E. The ON TRAC model for transitional care of adolescents. Prog Transplant 2006;16:291-302 3. Janet E McDonagh et al, J Child Health Care 2006;10(1):22-42." Further information can be found at www.uhs.nhs.uk/readysteadygo April 2020. 2518

The Ready Steady Go transition programme - Steady

The medical and nursing team aim to support you as you get older and help you gradually develop the confidence and skills to take charge of your own healthcare.

Filling in this questionnaire will help the team create a programme to suit you.
Please answer all questions that are relevant to you and ask if you are unsure.

Name: Date:

Knowledge and skills	Yes	I would like some extra advice/help with this	Comment
KNOWLEDGE			
I understand the medical terms/words and procedures relevant to my condition			
I understand what each of my medications are for and their side effects			
I am responsible for my own medication at home			
I order and collect my repeat prescriptions and book my own appointments			
I call the hospital myself if there is a query about my condition and/or therapy			
I know what each member of the medical team can do for me			
I understand the differences between children's and adult health care			
I know about resources that offer support for young people with my condition			
SELF ADVOCACY (speaking up for yourself)			
I feel confident to be seen on my own for some/all of each clinic visit and to ask my own questions			
I understand my right to confidentiality			
I understand my role in shared decision making with the healthcare team e.g. Ask 3 Questions*			
HEALTH AND LIFESTYLE			
I exercise regularly/have an active lifestyle			
I understand the risks of drugs, alcohol and smoking to my health			
I understand what appropriate eating means for my general health			
I am aware that my condition can affect how I develop e.g. puberty			
I know where and how I can access reliable information about sexual health			
I understand the implications of my condition and medications on pregnancy/parenting (if applicable)			

*See www.uhs.nhs.uk/Media/UHS-website-2019/Patientinformation/Childhealth/ReadySteadyGo/Printready/Ready-Steady-Go-postcard-print-ready.pdf

The Ready Steady Go transition programme - Steady

Knowledge and Skills	Yes	I would like some extra advice/help with this	Comment
DAILY LIVING			
I can look after myself at home in terms of dressing and bathing/showering etc			
I can make my own snacks/meals			
I know how to plan ahead for being away from home, overseas, trips, e.g. storage of medicines and vaccinations			
EDUCATION AND YOUR FUTURE			
I am managing at school/college (getting to and from the site, coping with work, friends and PE, for example)			
I know what I want to do when I leave school			
I have had work/volunteering experience			
I am aware of any potential impact of my condition to my education and/or work opportunities			
I know who to contact for careers advice			
LEISURE			
I can use public transport and access my local community, e.g. shops, leisure centre, cinema			
I see my friends outside school/college			
MANAGING YOUR EMOTIONS			
I know how to deal with unwelcome comments/ bullying			
I know someone I can talk to when I feel sad/fed up			
I know how to deal with emotions such as anger or anxiety			
I am comfortable with the way I look			
I am happy with life			
TRANSFER TO ADULT CARE			
I understand the meaning of 'transition'			
I am aware of the plan for my medical care when I am an adult			
I have all of the information I need about the adult team who will be looking after me			

Please list anything else you would like help or advice with:

Thank you

The Ready Steady Go materials were developed by the Transition Steering Group led by Dr Arvind Nagra, paediatric nephrologist and clinical lead for transitional care at Southampton Children's Hospital, University Hospital Southampton NHS Foundation Trust based on the work of: 1. S Whitehouse and MC Paone. Bridging the gap from youth to adulthood. Contemporary Pediatrics; 1998, December. 13-16. 2. Paone MC, Wigle M, Saewyc E. The ON TRAC model for transitional care of adolescents. Prog Transplant 2006;16:291-302 3. Janet E McDonagh et al, J Child Health Care 2006;10(1):22-42. Users are permitted to use 'Ready Steady Go' and 'Hello to adult services' materials in their original format purely for non-commercial purposes. No modifications or changes of any kind are allowed without permission of University Hospital Southampton NHS Foundation Trust.

The following acknowledgement statement must be included in all publications which make reference to the use of these materials: "'Ready Steady Go' and 'Hello to adult services' developed by the Transition Steering Group led by Dr Arvind Nagra, paediatric nephrologist and clinical lead for transitional care at Southampton Children's Hospital, University Hospital Southampton NHS Foundation Trust based on the work of: 1. S Whitehouse and MC Paone. Bridging the gap from youth to adulthood. Contemporary Pediatrics; 1998, December. 13-16. 2. Paone MC, Wigle M, Saewyc E. The ON TRAC model for transitional care of adolescents. Prog Transplant 2006;16:291-302 3. Janet E McDonagh et al, J Child Health Care 2006;10(1):22-42." Further information can be found at www.uhs.nhs.uk/readysteadygo April 2020. 2518

The Ready Steady Go transition programme - Go

The medical and nursing team aim to support you as you get older and help you gradually develop the confidence and skills to take charge of your own healthcare.

Filling in this questionnaire will help the team create a programme to suit you.
Please answer all questions that are relevant to you and ask if you are unsure.

Name: Date:

Knowledge and skills	Yes	I would like some extra advice/help with this	Comment
KNOWLEDGE			
I am confident in my knowledge about my condition and its management			
I understand what is likely to happen with my condition when I am an adult			
I look after my own medication			
I order and collect my repeat prescriptions and book my own appointments			
I call the hospital myself if there is a query about my condition and/or therapy			
SELF ADVOCACY (speaking up for yourself)			
I feel confident to be seen on my own in clinic			
I understand my right to confidentiality			
I understand my role in shared decision making with the healthcare team e.g. Ask 3 questions*			
HEALTH AND LIFESTYLE			
I exercise regularly/have an active lifestyle			
I understand the risks of drugs, alcohol and smoking on my condition and general health			
I understand what appropriate eating means for my general health			
I know where and how I can access reliable information about sexual health			
I understand the implications of my condition and medications on pregnancy/parenting (if applicable)			
DAILY LIVING			
I am independent at home – dressing, bathing, showering, preparing meals, etc			
I can or am learning to drive			

*See www.uhs.nhs.uk/Media/UHS-website-2019/Patientinformation/Childhealth/ReadySteadyGo/Printready/Ready-Steady-Go-postcard-print-ready.pdf

The Ready Steady Go transition programme - Go

Knowledge and Skills	Yes	I would like some extra advice/help with this	Comment
DAILY LIVING (CONTINUED)			
I know how to plan ahead for being away from home, overseas, trips e.g. storage of medicines, vaccinations			
I understand my eligibility for benefits (if applicable)			
EDUCATION/WORK AND YOUR FUTURE			
I have had work/volunteering experience			
I have a Career Plan (please specify)			
I am aware of the potential impact (if any) of my condition on my future career plans			
I know how and what to tell a potential employer about my condition (if applicable)			
I know who to contact for careers advice			
LEISURE			
I can use public transport and access my local community, e.g. shops, leisure centre, cinema			
I see my friends outside school/college/work			
MANAGING YOUR EMOTIONS			
I know how to deal with unwelcome comments/ bullying			
I know someone I can talk to when I feel sad/fed-up			
I know how to cope with emotions such as anger or anxiety			
I know where I can get help to deal with my emotions if needed			
I am comfortable with the way I look			
I am happy with life			
TRANSFER TO ADULT CARE			
I understand the meaning of 'transition' and transfer of information about me			
I know the plan for my care when I am an adult			
I have all of the information I need about the adult team who will be looking after me			

Please list anything else you would like help or advice with:

Thank you

The Ready Steady Go materials were developed by the Transition Steering Group led by Dr Arvind Nagra, paediatric nephrologist and clinical lead for transitional care at Southampton Children's Hospital, University Hospital Southampton NHS Foundation Trust based on the work of: 1. S Whitehouse and MC Pacone. Bridging the gap from youth to adulthood. Contemporary Pediatrics; 1998, December. 13-16. 2. Paone MC, Wigle M, Saewyc E. The ON TRAC model for transitional care of adolescents. Prog Transplant 2006;16:291-302 3. Janet E McDonagh et al, J Child Health Care 2006;10(1):22-42. Users are permitted to use 'Ready Steady Go' and 'Hello to adult services' materials in their original format purely for non-commercial purposes. No modifications or changes of any kind are allowed without permission of University Hospital Southampton NHS Foundation Trust.

The following acknowledgement statement must be included in all publications which make reference to the use of these materials: "Ready Steady Go' and 'Hello to adult services' developed by the Transition Steering Group led by Dr Arvind Nagra, paediatric nephrologist and clinical lead for transitional care at Southampton Children's Hospital, University Hospital Southampton NHS Foundation Trust based on the work of: 1. S Whitehouse and MC Paone. Bridging the gap from youth to adulthood. Contemporary Pediatrics; 1998, December. 13-16. 2. Paone MC, Wigle M, Saewyc E. The ON TRAC model for transitional care of adolescents. Prog Transplant 2006;16:291-302 3. Janet E McDonagh et al, J Child Health Care 2006;10(1):22-42." Further information can be found at www.uhs.nhs.uk/readysteadygo April 2020. 2518