Position Statement

Transition of Young People from Paediatric to Adult Health Services

Children's Health Scotland (previously Action for Sick Children Scotland) works for the best quality of healthcare to be provided for all children and young people at times of illness or when required to maintain health for those with chronic conditions.

Context

Transition in healthcare describes the process by which the individual moves from one form of clinical management to another over a period of time. This can vary from weeks e.g. for discharge from hospital to community care to months and to years e.g. for young people dealing with the late effects of cancer therapy.

The World Health Organisation and United Nations define children as those under the age of 18.

The UN Convention on the Rights of the Child[i] and the Children and Young People (Scotland) Act 2014 accept up to the age of 18 as legally requiring access to protection, access to education and appropriate healthcare. Health professionals providing care to children and young people should be trained in the assessment of health needs of different age groups.

The EACH Charter[ii] for children and young people sets standards for the care of sick children in hospital and has been adopted by the Scottish Government. Currently Scottish hospitals admit most children up to the age of 16 although there are exceptions in some cases of specialist services, and in some mental health units. Children's Health Scotland regards it unacceptable for age appropriate care to be denied to any young person on the basis of lack of accommodation or inappropriately trained staff.

Recommendations

Healthcare Rights: Children's Health Scotland believes that all children and young people should be informed of their healthcare rights and supported to understand how to look after their health, both physical and mental, know what to do if they are unwell and how to access health services when they are needed.

Self-management: For children with chronic conditions their healthcare from diagnosis is aimed at optimal health with awareness that they are expected to require lifelong review and treatment. Adopting a self-management approach from the start helps children to develop self-efficacy which has been shown to reduce the risk for adolescents with chronic disease withdrawing from treatment programmes.

Education: Children's Health Scotland emphasises the importance for young people of their access to education, both to minimise an adverse effect on their academic performance, but also on their social links and peer support. Every young person who has to be absent from education due to ill health must be offered access to support for learning both while in hospital or ill at home. Those with long term conditions should also have access to appropriately trained career advisors to optimise their opportunities for employment and career progression

Physical Activity: Wherever possible, young people should be encouraged to see physical activity and exercise as an important element of health maintenance. When in hospital their recovery can be enhanced and long term health improved by the inclusion of physical activity in their treatment plans. If this can be planned to provide social contact within an age appropriate environment then this may offer additional benefits.

Partnerships: Children's Health Scotland welcomes the emphasis placed by the Chief Medical Officer on partnership medicine and the potential this offers for young people to make a smooth transition from paediatric to adult health services. For children and young people the partnership involves parents or carers to a reducing degree as adolescence progresses. The expectation that the clinical care of the young person will change over the same period of adolescent development must be adapted to the wishes and needs of the young person and their family as well as the healthcare providers and facilities.

Transition Planning: Children's Health Scotland strongly supports the recommendations of the Think Transition Report of the Royal College of Physicians of Edinburgh (RCPE)[iii] and the Royal College of Paediatrics and Child Health (RCPCH) Transition Making it Happen event, reported by the Long Term Conditions group of the Scottish Government[iv], that transition should be planned from the time of diagnosis with an agreed stepwise plan for transfer of services over the adolescent period, which includes a named transition key worker, agreed with the young person and their advocate.

The key person should accompany the young person to the initial introduction to the adult team, to shared clinics for joint review, and to their initial adult service assessments where procedures may differ from the children's service areas, and where the young person's confidence may be threatened by the unfamiliar surroundings.

Adult Health Services: Adult specialist teams should be encouraged to access continuous professional development (CPD) on adolescent health. At least one member of each team should be supported to extend their knowledge and skills in supporting the mental health of young people, as this is an area of concern to young people and their carers and is likely to impact on their resilience in coping with transition to a new environment of care.

It would be important that adult health services actively follow up young people who fail to attend (DNA) or are not adhering to treatment regimes after transition, given their developmental vulnerabilities and the long term impact of not receiving treatment.

Coordinated Care: Many children and young people with chronic conditions have been seen and treated by specialists from several different specialties, while under the care of a paediatric team that coordinates the care, whose members are known to the young person and their family and are available to support the family with contacts and reviews by others.

In adult services there is no generic standard of coordination around the individual with each specialty working separately, often with several multi-disciplinary teams seeing the same patient, who is expected to manage the demands of each team including multiple appointments, prescriptions, medications and monitoring requirements. For the young person coping with the challenges of adolescence this tsunami of change can be overwhelming, while parents and carers try to relinquish their responsibilities for implementing clinical management plans.

Children's Health Scotland suggests that the benefits of coordinated care for individuals with chronic disease in later years should be applied to young people in transition to adult health services. It may be helpful to consider the steps that have led to the LAAC Director in every Health Board to hold responsibility for the healthcare of children and young people in and leaving care.

Health Boards: Each Health Board should have a robust policy for the provision of healthcare for adolescents and those moving from paediatric to adult services.

Policies and Procedures: We ask for an executive member of each Health Board to have responsibility for transition policies and procedures for young people with chronic disease or complex disabilities. This senior role should have line management for those health professionals and advocates who are nominated as key workers for individual young people, with authority to ensure that the needs of the individual young person are considered in relation not only to age and maturity, but also the life events that may impact on their ability to cope with transfer of care at a specific time.

References:

United Nations Convention on the Rights of the Child
[i] https://downloads.unicef.org.uk/wp-content/uploads/2010/05/UNCRC_united_nations_convention_on_the_rights_of_the_child.pdf

[ii] European Association for Children in Hospital: EACH Charter
https://www.each-for-sick-children.org/each-charter

[iii] AR Watson: J R Coll Physicians Edinb 2012; 42:3–4 doi:10.4997/JRCPE.2012.101
https://www.rcpe.ac.uk/sites/default/files/editorial-1.pdf

[iv] Principles of Good Transitions 3
https://scottishtransitions.org.uk/7-principles-of-good-transitions/

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