PHuman™
Self-Management Series

WEBINAR: Growing up with PH and the role of parents and family

Episode 12 – Tuesday 25 February 2020

DISCUSSION SUMMARY

Overview

On Tuesday 25 February 2020, Actelion hosted a webinar entitled '**Growing up with PH and the role of parents and family**'. Simon Stones, Patient Advocate and Consultant was the guest speaker. During his presentation Simon provided a definition of transition, discussed key issues and concerns about transitioning to adult healthcare services and shared strategies to help facilitate transition between young people, their families and healthcare professionals (HCPs).

The primary objectives of the webinar were:

- To discuss the transition from child to adult healthcare for those living with a chronic condition like PH, and the role of parents and family when undertaking and supporting this process
- To share best practice approaches to help support conversations between HCPs and young people living with PH, along with their parents/carers, on transitional care
- To identify sources of quality information on transitional care to support children with PH, their parents and families, in the best management of this process

Discussion summary and key learnings

Defining transition

- Transition is a purposeful, planned process that addresses the medical, psychosocial, educational and vocational needs of adolescents and young adults with chronic health conditions, as they move from child-centred to adult-oriented healthcare systems and services
- It is important to note that transition is **not the same as transfer**, the event of moving from pediatric to adult healthcare services, as it includes the planning and preparation before the transfer, the actual event of transfer and the support received after transfer

Why is transition important?

- Pediatric and adult healthcare services are quite different, for example:
    - Pediatric care is family-focused, socially orientated, relaxed, informal and usually delivered by a multidisciplinary team
    - Adult care is patient-focused, disease orientated, formal with a narrower focus and delivered by individual teams with some co-operation
- Transition is important because it can support young people and their families to navigate between these two healthcare services and enable young adults to develop confidence and competencies to manage their health independently
- Failure to plan for the transition can reduce patient engagement with health services. Currently, young people are less likely to go to hospital appointments and to comply with treatments after transfer. This increases the likelihood of health conditions worsening. It can also affect a young person's education, work-life and family dynamic

Barriers to successful transition

- Transition is a complex process that involves:
  - Numerous healthcare systems, structures, processes e.g. different appointments, waiting times, information and resources
  - Supporting young people to grow capacity to self-care/manage the condition
  - Promoting autonomy in young people and principles of adolescent medicine e.g. influence of peers and the role of parents and carers
- There are usually a number of people involved, for example: PH specialists, psychologists, nurses, pharmacists, family members, employers, admin staff, health social workers etc.
- The complexities of transition and the large number of people involved can make it difficult for things to 'join up' during the process
- The main barriers to enabling successful transitions include:
  - lack of specialist knowledge in adult healthcare teams
  - lack of specialist services for young people,
  - lack of understanding and appreciation of young people's needs and issues,
  - lack of self-advocacy skills and lack of opportunity to develop and practice these skills among young people[i]

How can we support young people with the transition process?

Planning for transition

- Planning should start as early as possible to make sure young people are ready for the transfer to adult healthcare services
- During the planning process, families and healthcare teams should gradually support the young person in handling their type of PH. This could include teaching the young person about their PH, building confidence in the young person to grow their capacity for self-care/management, discussing the different healthcare processes and promoting autonomy etc. It is recommended that information is gradually provided to the young person to prevent them from feeling overwhelmed when the transfer to adult healthcare occurs
- To support individuals in navigating the healthcare systems and to grow self-management skills, a key accountable individual should work with the young person to guide them through the process - this could be a nurse or dedicated social worker
- Transition plans should be well documented and include the young person's individual needs to ensure all relevant professionals have access to essential information about the young person. A good example of this is the 'Health Passport' used by the National Health Service in the UK. The passport provides a place for a young person to track their needs and includes three main sections: 'things you must know about me', 'things that are important to me' and 'my likes and dislikes'[ii]

At stages in the process: the voice of young people and their families must be heard!

- Every young person is different and has individual needs, it is important for parents and healthcare teams to listen to the young person to understand their needs and tailor their transition plan accordingly
- The National Institute for Health and Care Excellence (NICE) in the UK provide useful guidance[iii]:
  - Transition support should be strength-based and focused on what is positive and possible for the young person rather than on a pre-determined set of transition options
  - Teams should support the young person to make decisions and build their confidence to direct their own care and support over time
  - Parents/carers should regularly ask the young person how they would like them to be involved – some people might find it useful for their parent/carer to continue coming with them to appointments, to capture notes and improve discussion, whereas others may prefer greater autotomy
  - HCPs should address all relevant outcomes, including those related to: education, employment, community inclusion, health and wellbeing (including emotional health), independent living and housing options

    - If a young person does not attend appointments, adult services should try to contact the young person and their family, and involve other relevant professionals, including the GP
- Listening to a young person's needs will enable teams to agree the best time for that person to transition – it was noted that 16 might not be the right age for everyone to transition

Young people and their families should have access to peer support and information to help them with the process

- Mentor schemes can help young people connect to others who are further on in their journey. This can provide the opportunity for young people to learn from their experiences and feel more supported
- Patient associations can help provide training to mentors, connect young adults and provide information on learning self-management/advocacy skills. Mobile technology and social media can also support with connections

Conclusion

- To enable a successful transition to adult healthcare services, it is important to:
    - Start the process early and plan for the transfer
    - Tailor the transition plan to the young adult
    - Document their progress and regularly review
    - Ensure effective communication between everyone involved e.g. HCPs, nurses, social workers, parents, teachers etc
- Throughout the process, it is vital to listen to the young person (and their family) to understand their individual needs and desires, and ensure their transition is tailored accordingly

Appendix

- For more information about coping with PH visit: https://phassociation.org/patients/living-with-ph/coping-with-ph/
- To listen to personal stories about PH and the transition to adult healthcare visit: The PHaware podcast - I'm Aware That I'm Rare: https://www.phaware.global/podcast

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i Royal College of Nursing (2013). Adolescent transition care.

[ii] Care Quality Commission (2014). From the pond into the sea: Children's transition to adult health services.

iii National Institute for Health and Care Excellence (2016). Transition from children's to adults' services for young people using health or social care services