Roadmap to sustainable healthcare: how to improve the transition for adolescents from paediatric to adult health and care

If we are to achieve sustainable healthcare, we need to focus upstream on people who will live with a long-term condition for most of their lives. Late teenage years can be a turbulent period for young people, especially for those living with long-term conditions, as making the transition from paediatric to adult care settings can add unwanted pressure.

Transition is a make or break period; if managed correctly, it can empower young people to take greater ownership and management of their conditions. If managed incorrectly, or worse, not done at all, the transition period can see adolescents disengage and drop out of contact with the health system altogether, often with severe consequences.

However, we should not underestimate teenagers’ ability to manage their own health. Research conducted in 2016 on behalf of Abbvie UK and the College of Medicine showed that 8 out of 10 adolescents “feel confident about looking after their own health.” The health and education system should therefore seek to empower young people with long-term conditions by giving them the tools to do so. This will not only deliver better health outcomes, but also create efficiencies in the health system as a whole. Making health and wellbeing education in schools more inspiring, relevant and effective will play its part, but expert advice and support from healthcare professionals who are receptive to the needs of young adults will be key, especially for those transitioning through services.

In 2016, the National Institute for Health and Care Excellence (NICE) found that there is “a wealth of policy and guidance on agreed principles in respect of good transitional care, but there is also evidence that these principles are often not reflected in practice.” To address this challenge, in July 2017, AbbVie convened a breakfast discussion in Manchester where attendees heard from a panel of experts who offered their perspectives on how care for young people with long-term conditions could be improved. A number of recommendations stemmed from this discussion.

- Health system leaders should support the drive to embed excellent transition as a standard part of the service

Local system leaders do not give transition services the level of priority that they should. Transition services are often described as being perceived by decision-makers to be a “luxury service”. Despite the growing wealth of guidance available, good transitioning practice frequently fails to be translated into local policies and protocols.

- Healthcare commissioners and providers should audit local service provision against the markers of quality identified by NICE
Nick Baillie, Associate Director for Quality and Leadership at NICE, highlighted the recently published NICE guideline and the quality standard on the transition from children’s to adults’ services. The guideline provides a range of evidence based recommendations on this issue for individual practitioners and young people. The quality standard provides a succinct, evidence-based description of the most important areas for quality improvement for commissioners and leaders. Unfortunately, there remains a gap between the aspirational standards of quality described by NICE guidance and practice.

- **Transition service should be tailored to the individual, placing them at the centre of their care**

The principles of shared decision-making are too often not applied in transitioning, as demonstrated by a recent Care Quality Commission-supported survey of 11-14 year olds which found that they were not as involved in their care as they would have wanted to be. As Kath Evans, Experience of Care Lead at NHS England, pointed out, young people’s participation and engagement are crucial to success. Involving young people in the decisions about their care and listening to their concerns and preferences will allow for the delivery of individually tailored transitions. Without placing the person at the centre of their care and fully involving them in decision-making, a personalised transition service is not possible. Existing tools such as Ready, Steady, Go, Hello, developed by Southampton University Hospital, can support collaborative conversations about the breadth of issues that affect young adults beyond purely their health issue.

- **The NHS needs to capitalise on the potential of digital platforms to offer readily accessible clinical advice and facilitate peer-to-peer support**

To reach young people, one must speak their language. As remarked by Andrea McBride, the Founder of Arthur’s Place, the everyday communication and engagement in the lives of young people today "happens in the digital space, but the NHS isn’t there". Digital platforms are where many young people feel comfortable and health services need to make a concerted effort to capitalise on the opportunities this offers.

Arthur’s Place, a website and social network for young people with arthritis, offers a great example of the effectiveness with which online media can increase the engagement of young people in their care. Arthur’s Place is a source of readily accessible nursing advice for its more than 450 users. It offers a forum for young people to connect with their peers who may be undergoing similar experiences. Peer-to-peer support and a sense of community can go a long way in encouraging young people to stay engaged in the management of their condition.

Further to the benefit of the individuals involved, a cohesive online community offers opportunities for young people to speak with a united voice, empowering them to demand improvements in services.

AbbVie is currently working with the founders of Arthur’s Place to explore the opportunities of adapting their tested model in other disease areas, giving young people online access to professional advice and peer-to-peer support.

- **NHS organisations, supported by the stakeholder community, should work together to identify and effectively share examples of best practice**

Arthur’s Place is just one example of digital media being used to successfully drive engagement with health services. Skype conversations offered to young people with diabetes by the Newham University Hospital and the NHS Go app were but two of the many effective digital health initiatives across the country mentioned at the event. In order to reap the full benefit of the digital promise, best practice from across the NHS should be effectively shared and adapted to other areas of the country.

- **Healthcare professionals involved in transitioning should be provided with the training and support they need to deliver services in line with NICE guidance**

The gap between the theory of good transitioning practice and the reality will only be bridged when healthcare professionals receive the training and support to empower them to make a difference. Dr Candice Pellett OBE,
Transition Project Manager at the Queen’s Nursing Institute, has led on the creation of a learning resource aimed at community nurses. Informed by surveys and focus groups with the target audience, the resource offers the tools and support required by community nurses, enabling them to help young people through the service transition.

However, the nursing community is just one piece of the puzzle. Transition from children's to adults' services is a complex process, involving a range of specialisms. Healthcare practitioners from across the patient pathway will all need to play their part to ensure young people with long-term conditions receive the holistic, joined-up and continued care through their transition to adult services.

As Kath Evans remarked, “Young adulthood is a complicated, developmental phase which deserves greater attention. It should be remembered that not all young adults will transition from paediatric services, many will ‘crash land’ into adult services. Our services must better recognise and address the specific challenges young adults face in managing long term health conditions at a complex time in their lives.”

Speakers

- Chair: Carrie Grant, broadcaster with personal experience of transition issues
- Dr Candice Pellett OBE, Transition Project Manager at the Queen's Nursing institute
- Andrea McBride, the Founder of Arthur’s Place
- Kath Evans, Experience of Care Lead at NHS England
- Nick Baillie, Associate Director for Quality and Leadership at NICE
- Simon Stone, patient who has been through the transition from paediatric to adult services

AbbVie’s commitment to sustainable healthcare

The Sustainable Healthcare Initiative was established in 2015 as a partnership between AbbVie and the College of Medicine. As a biopharmaceutical company in the 21st century, AbbVie is committed to addressing the healthcare challenges in society differently. AbbVie’s approach to healthcare not only includes helping people to live longer but also live better.

AbbVie’s vision is to help build a sustainable future for our health system. Life-long prevention, early diagnosis and integrated care of chronic diseases must be embraced to extend the healthy life years of our aging population and ensure the health and care system is prepared and equipped to support this. New approaches are required to address the challenges our society faces today.

2 NICE, Transition from children’s to adults’ services for young people using health or social care services, 2016, https://www.nice.org.uk/guidance/ng43/resources/transition-from-childrens-to-adults-services-for-young-people-using-health-or-social-care-services.pdf