

## Stepping Up Support for Young People with Chronic Illnesses

*Ireland's first website to help young people move from child to adult care services launched*

**DUBLIN - December 3<sup>rd</sup>, 2013** – A new resource to help young people with long-term illnesses make the transition into adult health services was launched on December 3<sup>rd</sup> by Alan Sothorn, Irish International hockey player who has Type 1 diabetes.

Developed by Professor Coyne and a team of researchers in Trinity College Dublin's [School of Nursing and Midwifery](#), in partnership with young people with long-term illnesses, such as cystic fibrosis, Type 1 diabetes and congenital heart disease, [SteppingUP.ie](#) offers video testimonials, downloadable stories and tips and information on managing the transition, becoming more independent, knowing about medications and the differences between child and adult services.

Findings from a major research project being conducted at the School of Nursing and Midwifery have shown that young people with long-term illnesses, need better support and preparation to make a successful and positive transition from accessing health supports in a children's hospital environment to an adult health system.

Professor Imelda Coyne, lead researcher for the [SteppingUP.ie](#) project and Professor in Children's Nursing at the [School of Nursing and Midwifery](#), Trinity College Dublin said: "At the moment in Ireland, there is very little information available to young people and their families on the transition process. This website is the first of its kind and we hope that it will be useful for young people who are thinking about and planning to make the transition to adult services, as we know from our research that the move can be difficult for some. SteppingUP.ie is one way of helping equip young people with knowledge and skills so that the move to adult services is made a bit easier."

Launching the SteppingUP.ie website today, Alan Sothorn, Irish International hockey player who has Type 1 diabetes said: "The support and guidance that SteppingUP.ie is offering is exactly what young people with diabetes need at this time in their lives. I am absolutely delighted to see a website solely dedicated to helping young people transition into adult care as personally I feel this is something I certainly would have benefitted from during that time. With so many changes happening around this age, the worry of transitioning from childcare to adult services in as seamless a manner as possible is something that shouldn't impact those affected, which prior to this website it may have. "

The project team adopted a participatory approach viewing the young people, with long-term illnesses, as a central element in the design and development of the site and its content. Young people took part in participatory workshops, one-to-one interviews and video recordings and were part of a co-design group.

Darren O'Toole was diagnosed with Type 1 diabetes at the age of five and attended the children's clinic every three months. He made the transition to adult care at the age of 18 and is now 23 years old and studying Bio-technology at NUI Maynooth. Commenting on his involvement in co-developing [SteppingUP.ie](#) with the team at Trinity College Dublin, Darren said: "I was grateful to be included as it felt fulfilling to give something back. Putting my own

illness experiences into a context that would assist others with the same illness felt really rewarding. I jumped at the opportunity to help with the project and enjoyed every aspect of it. Transition is progression and progression is positive and so is 'SteppingUp.ie'."

Speaking about the challenges with the transition period to adult services, Dr Kevin Moore, Consultant Endocrinologist, Tallaght Hospital Dublin and Clinical Senior Lecturer in Endocrinology at Trinity said: "For young people, with long-term medical conditions, the period of transition from paediatric to adult services can be very difficult. We know that during transition, some patients lose contact with their health care professionals and may experience deterioration in their medical condition. The 'SteppingUP.ie' website will help young people to understand the process of transition and prepare for a safe and successful transfer of care to adult services."

The project was funded by the Health Research Board and received advisory support from Children in Hospital Ireland, Cystic Fibrosis Ireland, Diabetes Ireland and Heart Children Ireland.

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