

Transition for young people with intestinal failure

Information for Healthcare Professionals

By Angela Cole, Clinical Nurse Specialist for Children with intestinal failure

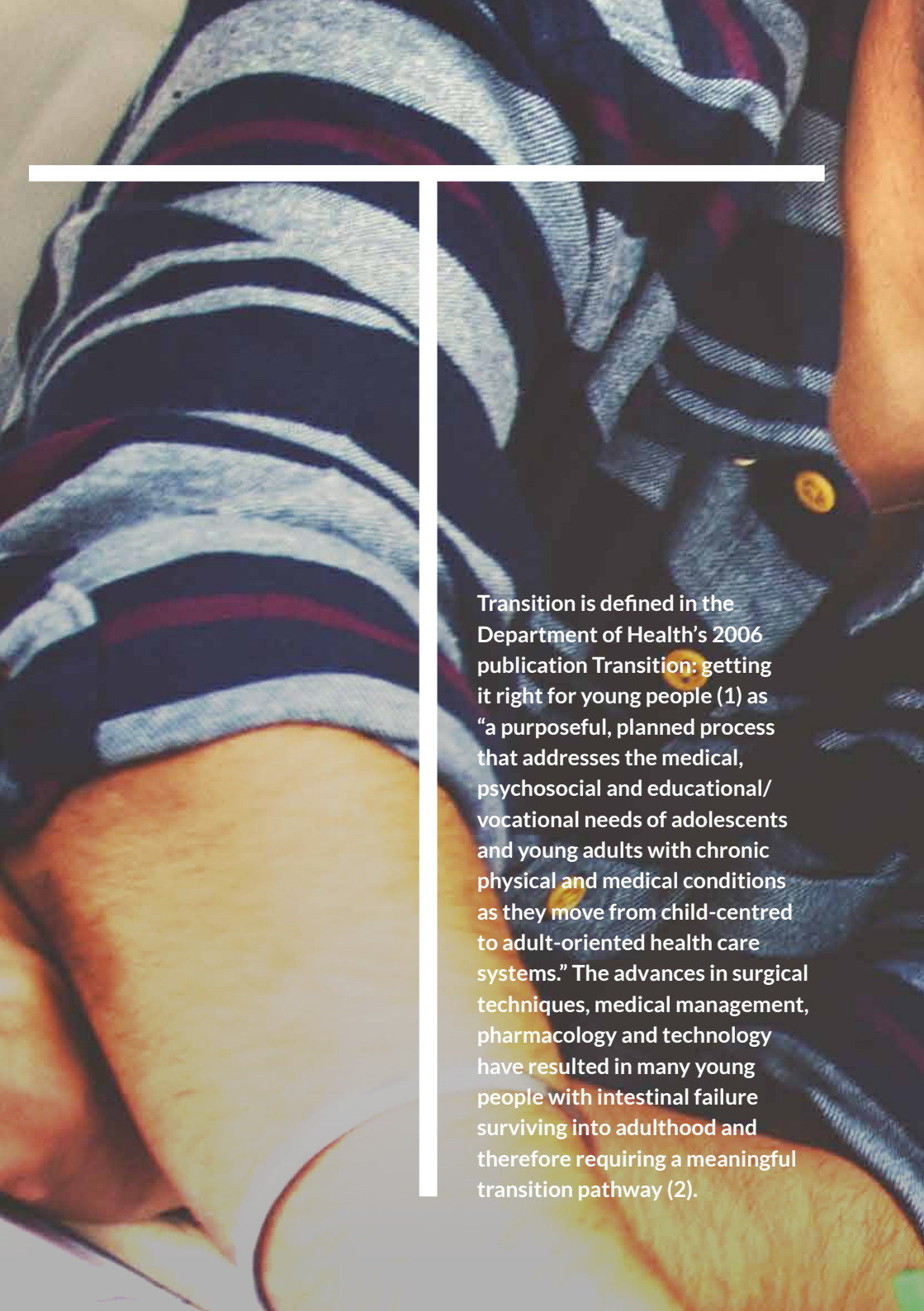
Transitioning young people
and families with childhood
onset intestinal failure
can be a challenge



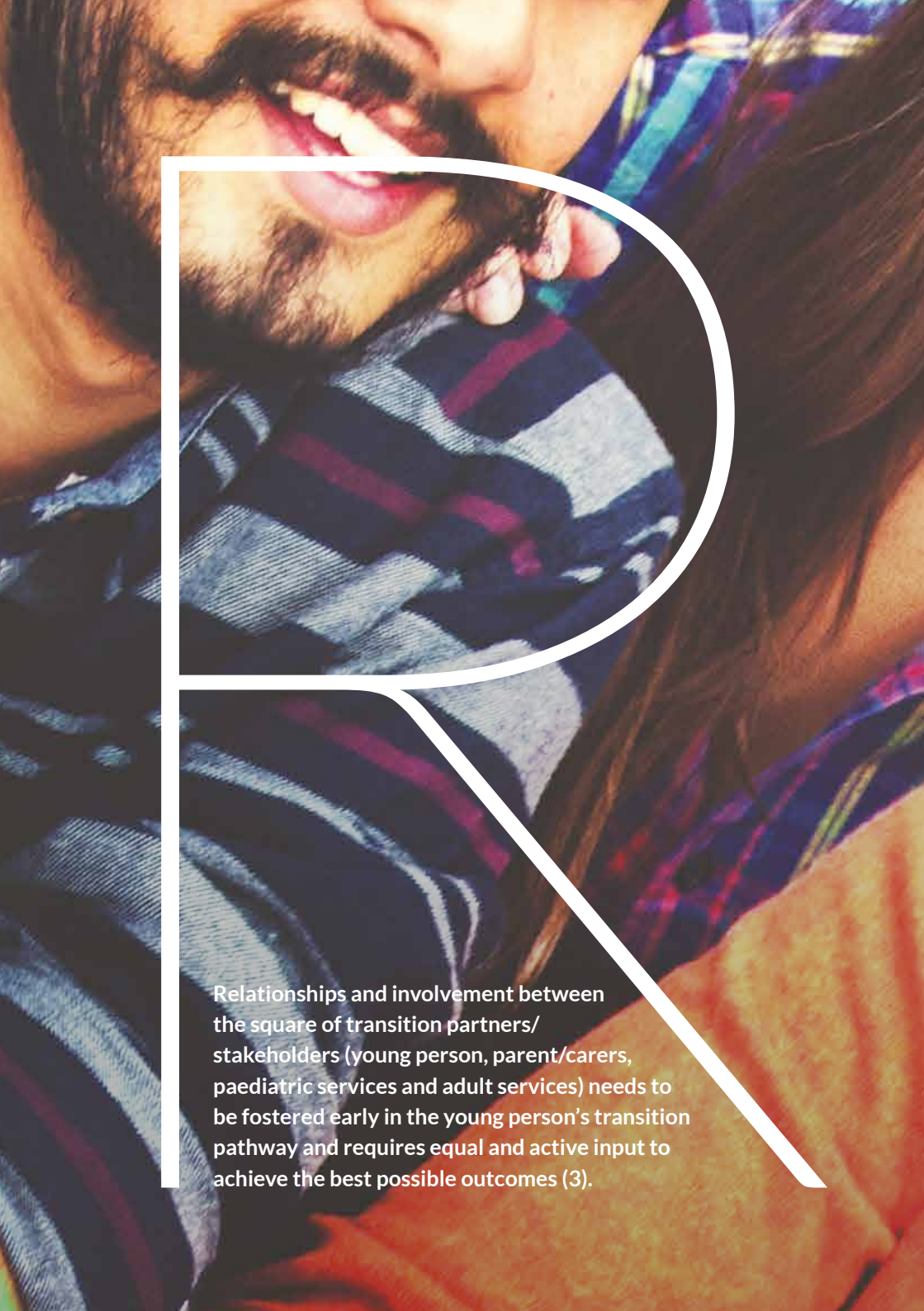
PINNT

Celebrated 30 years in 2017
Registered Charity: 1157655


We have highlighted the
key features to assist in the
transition pathway




Transition is defined in the Department of Health's 2006 publication *Transition: getting it right for young people* (1) 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." The advances in surgical techniques, medical management, pharmacology and technology have resulted in many young people with intestinal failure surviving into adulthood and therefore requiring a meaningful transition pathway (2).




Relationships and involvement between the square of transition partners/ stakeholders (young person, parent/carers, paediatric services and adult services) needs to be fostered early in the young person's transition pathway and requires equal and active input to achieve the best possible outcomes (3).



Adult services and what to expect. The young person needs to be equipped with the information and protocols to enable seamless contact and smooth access pathways when they enter into adult services. This information should be provided during the transition process and allow time for a question and answer session. This also includes any funding and equipment provision.




Negotiation and problem solving. Parents/Carers can find the transition pathways a time filled with anxiety and worry. This, coupled with a reduced role in their child's medical care, can result in an element of protectiveness that proves challenging to health care professionals. Negotiating and problem solving by working closely with the young person to allow empowerment whilst acknowledging the parent/carer's role in support and care, is important preparation that ensures the young person becomes empowered and feels supportedly independent (4).



Social, Education and Lifestyle. It is suggested that the transition process addresses the young person's lifestyle, future health concerns, educational/employment goals, psychosocial health, sexuality and reproduction (4).




Independence and Empowerment are key to future compliance and quality of life for the young adult. Health care professionals will need to have excellent communication pathways and knowledge/assessment skills of the young person's ability to become self caring. This process may require planning and a multi-disciplinary approach with professionals from outside health such as education and social care. Every young person should have an individual independence programme that is planned with the young person and parent/ carer to achieve compliance and fulfilment.



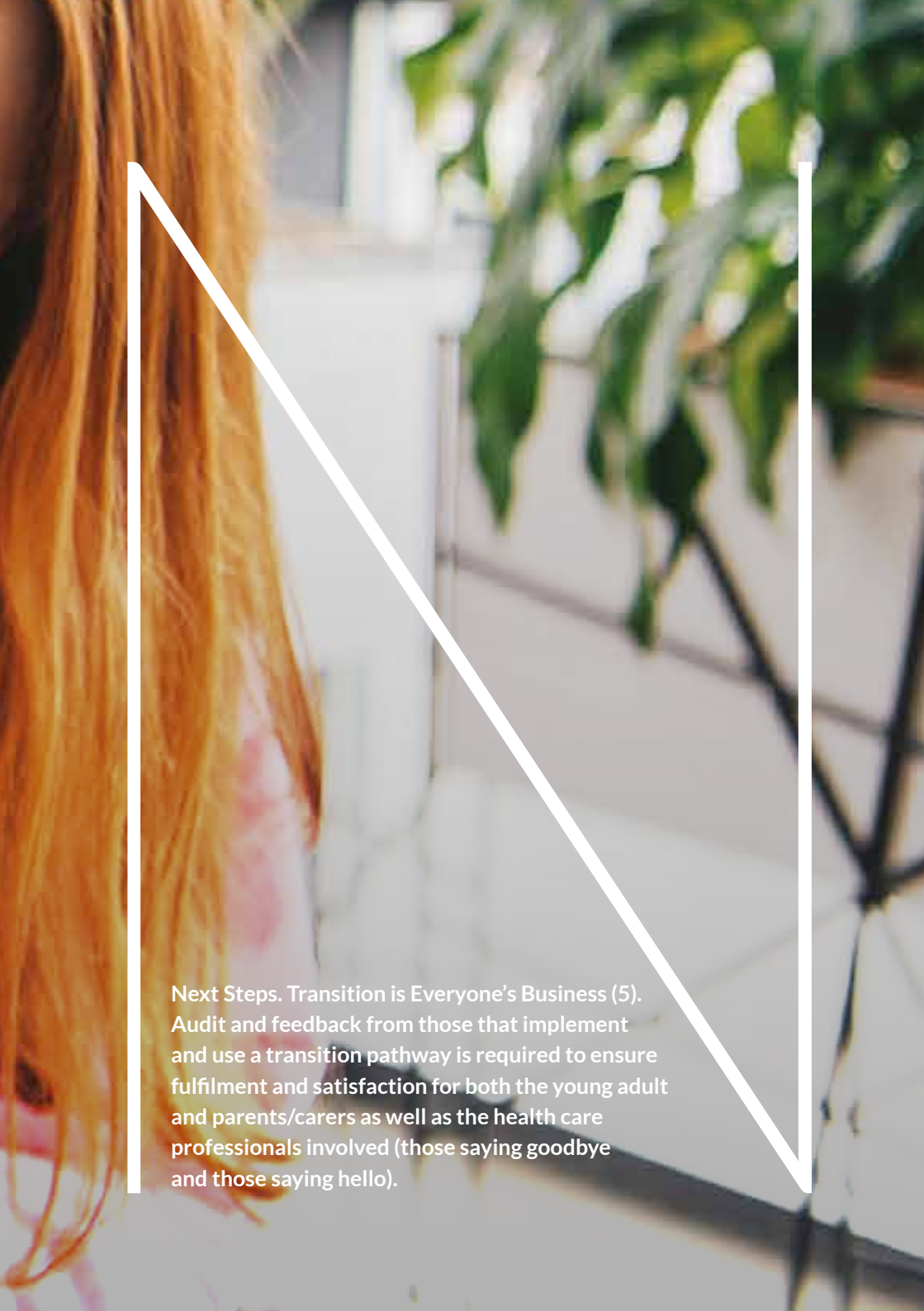
Timely and co-ordinated transition has been highlighted as an essential requirement to ensure that it is effective. The Transition process should commence prior to, or around, the age of 12 years. Transition requires resources such as a co-ordinator, young person-centred information and transition-centred clinics that incorporate both the paediatric and adult teams. (1,3,4)



Improves long-term outcomes for the young adult. Getting Transition right improves not only the young person's health outcomes but also those that impact on social and psychological wellbeing such as quality of life, future work and employment options and relationships. (1,3,4) Every young person has a right to a transition pathway that aims to get it right for the future.



Obstacles and Challenges. Most obstacles and challenges to Transition can be overcome with the early planning for a timely, individualised pathway. Communication and regular correspondence (written and verbal/face to face) between all the stakeholders will enable obstacles to be identified early and hopefully overcome. Some young adults will have multiple teams that provide care throughout health, continuing care, social care and education – all parties need to buy into the transition pathway, this can be a significant challenge. Education and Campaigns for awareness may be helpful, for example the ‘Everyone’s Business’ - Our Marvellous Transition Campaign from the Roald Dahl Marvellous Children’s Charity (5).



Next Steps. Transition is Everyone's Business (5). Audit and feedback from those that implement and use a transition pathway is required to ensure fulfilment and satisfaction for both the young adult and parents/carers as well as the health care professionals involved (those saying goodbye and those saying hello).

Useful resources



PINNT – www.pinnt.com

Contributors:

Angela Thompson – Roald Dahl Transition Nurse Specialist

Lizzie Hutchison – Paediatric Nutrition Nurse Specialist

Catriona McDonald – Paediatric Nutrition Nurse Specialist

References:

1. Department of Health, Transition: getting it right for young people, March 2006
2. Protheroe S, Symposium 6: Young people, artificial nutrition and transitional care Transition in young people on home parenteral nutrition: Conference on 'Malnutrition matters' 2009: published online Sep 1. DOI: <https://doi.org/10.1017/S0029665109990164>
3. From the pond into the sea. Care Quality Commission, 2014
4. Brooks AJ, Smith PJ, Cohen R, et al 2017: published online Feb 21. DOI:10.1136/gutjnl2016-313000
5. Dahl. Roald , 2019. <http://www.roalddahl.com/charity/transition>

www.pinnt.com
comms@pinnt.com

Follow us on
Facebook/Twitter
@PINNTcharity



PO Box 3126, Christchurch, Dorset, BH23 2XS

Designed by Graficstudio.co.uk