



ESOT TRANSPLANT LIVE

ONLINE
EDUCATION

Transition in pediatric transplantation

Moving together with the Generation Alfa

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Conflict of interest

I declare I have no conflict of interest

You are welcome to share details of this presentation responsibly and with due credit on social media.



What we will talk about

Definition of Transition

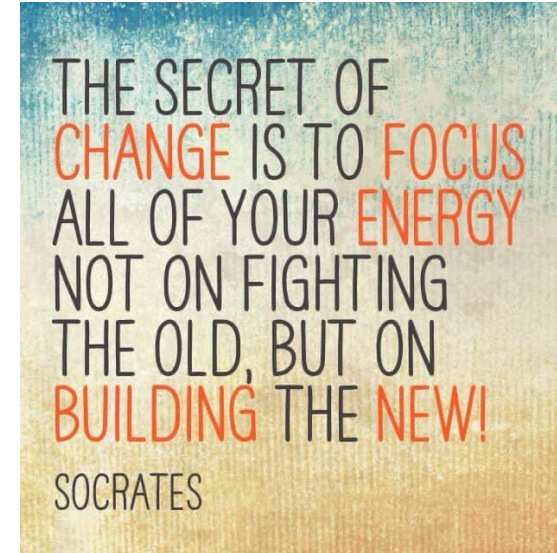
- Who?
- What?
- How?

‘Process or a period of **changing** from one state or condition to another’ *Merriam-Webster Dictionary*



**THE ART OF LIFE LIES IN
A CONSTANT READJUSTMENT
TO OUR SURROUNDINGS.**

KAKUZŌ OKAKURA,
THE BOOK OF TEA



Many speak of opportunities-
"When one door closes, another one
opens." But rarely about the hallway.
The transition. The in between where
you are and where you are headed.

The hallway doesn't have to be a
scary, dark, endless confusion- it can
be a space of massive transformation,
great memories, and peace.



Children & change

- Childhood-constant changes
- Significant events with different impacts
- Anticipated/expected vs unpredicted/unexpected/**unknown**
- Help and support



Greatest allograft failure is during or immediately after transition.

[BMJ Open](#). 2017; 7(6): e015593.

Published online 2017 Jun 12. doi: [10.1136/bmjopen-2016-015593](#)

PMCID: PMC5734418

PMID: [28606904](#)

Transition structures and timing of transfer from paediatric to adult-based care after kidney transplantation in Germany: a qualitative study

Jenny Prüfe,¹ Marie-Luise Dierks,² Dirk Bethé,³ Martina Oldhafer,⁴ Silvia Mütter,⁵ Julia Thumfart,⁶ Markus Feldkötter,⁷ Anja Büscher,⁸ Katja Sauerstein,⁹ Matthias Hansen,¹⁰ Martin Pohl,¹¹ Jens Drube,¹ Florian Thiel,¹² Susanne Rieger,¹³ Ulrike John,¹⁴ Christina Taylan,¹⁵ Katalin Dittrich,¹⁶ Sabine Hollenbach,¹⁷ Günter Klaus,¹⁸ Henry Fehrenbach,¹⁹ Birgitta Kranz,²⁰ Carmen Montoya,²¹ Bärbel Lange-Sperandio,²² Bettina Ruckebrod,²³ Heiko Billing,²⁴ Hagen Staude,²⁵ Reinhard Brunkhorst,²⁶ Krisztina Rusaj,²⁷ Lars Pape,¹ and Martin Kreuzer¹

[Review](#) > [Best Pract Res Clin Gastroenterol](#). 2003 Apr;17(2):277-89.

doi: [10.1016/s1521-6918\(02\)00144-0](#).

Transition of care between paediatric and adult gastroenterology. Liver transplantation

James M Neuberger¹

Affiliations + expand

PMID: 12676119 DOI: [10.1016/s1521-6918\(02\)00144-0](#)

> [Pediatr Nephrol](#). 2014 Sep;29(9):1617-24. doi: [10.1007/s00467-014-2809-4](#). Epub 2014 Apr 9.

Adherence to transition guidelines in European paediatric nephrology units

Thomas A Forbes¹, Alan R Watson, Aleksandra Zurowska, Rukshana Shroff, Sevcan Bakkaloglu, Karel Vondrak, Michel Fischbach, Johan Van de Walle, Gema Ariceta, Alberto Edefonti, Christoph Aufricht, Augustina Jankauskiene, Tuula Holta, Mesiha Ekim, Claus Peter Schmitt, Constantinos Stefanidis; European Paediatric Dialysis Working Group

> [Transplantation](#). 2009 Jun 15;87(11):1733-6. doi: [10.1097/TP.0b013e3181a63ed9](#).

Renal allograft loss during transition to adult healthcare services among pediatric renal transplant patients

Susan M Koshy¹, Diane Hebert, Kelvin Lam, Therese A Stukel, Astrid Guttmann

[Review](#) > [Pediatr Nephrol](#). 2011 Oct;26(10):1753-7. doi: [10.1007/s00467-011-1981-z](#).

Epub 2011 Aug 13.

Transition from pediatric to adult renal services: a consensus statement by the International Society of Nephrology (ISN) and the International Pediatric Nephrology Association (IPNA)

Alan R Watson¹, Paul Harden, Maria Ferris, Peter G Kerr, John Mahan, Maher Fouad Ramzy

> [Eur J Hum Genet](#). 2019 Dec;27(12):1783-1790. doi: [10.1038/s41431-019-0460-z](#).

Epub 2019 Jul 30.

Current management of transition of young people affected by rare renal conditions in the ERKNet

Martin Kreuzer¹, Jens Drube², Jenny Prüfe², Franz Schaefer³, Lars Pape²;

Members of the ERKNet Taskforce 'QoL & Transition'

'Adherence to guidelines significantly correlated with g

'Infrequent'

'Referrals too late'

[esot.org](#)

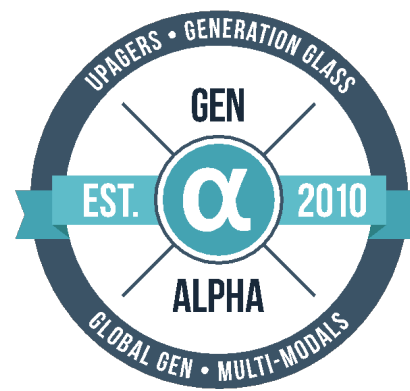


Who?

What?

How?

Who?



- Children and young people
- Childhood - crucial period in one's life
 - Growth, education, socialisation
- **Characteristics:**
 - digital natives
 - 'hyperconnected'
 - understanding of complex ideas



ESKD since infancy
Multiple kidney transplants
Multi-solid organ transplants
All delivered in crucial time-period

Vulnerable cohort in crucial life time period with burden of chronic condition

- **Unknown**/unpredictable/unexpected.
- How would you feel?



teenager

(noun)

When you're too young for half the things you want to do and too old to do the other half.

thatwhatthatmeans.tumblr.com

EVERY TEENAGERS # 271
TEENAGERS ARE THE MOST MISUNDERSTOOD PEOPLE ON THE PLANET. THEY ARE TREATED LIKE CHILDREN AND EXPECTED TO ACT LIKE ADULTS.

everyteenagers.tumblr.com

Telling a teenager the facts of life is like giving a fish a bath.

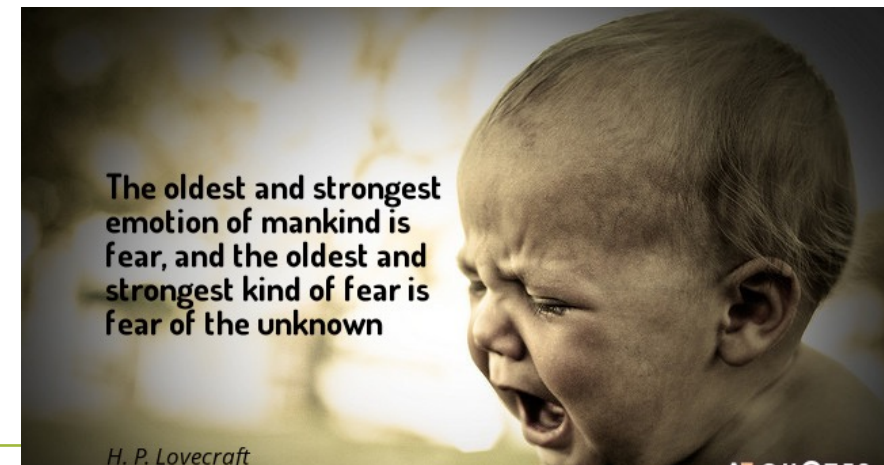
Arnold H. Glasow

BrainyQuote

What?

- Children are experts in adjusting to expected changes...
- Emotional
- Physical
- Intellectual
- Physiological

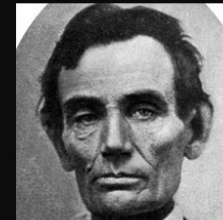
**They need guidance for unknown
Expect fear**



Team around the teenager

Young person

- Paediatricians - children's advocates
- Multi-disciplinary approach is essential
- Nephrologist, surgeon, urologist, anaesthetist, cardiologist, specialist nurses, theatre staff, coordinators, ITU specialists
- Play specialist, family therapist, psychologist, youth worker, school teacher, transition nurse +1
- Family and friends
- Aim for good clinical outcomes and improved QoL



The best thing about the future
is that it comes one day at a
time.

~ Abraham Lincoln

“Change is situational. Transition, on the other hand, is psychological. It is not those events, but rather the inner reorientation or self-redefinition that you have to go through in order to incorporate any of those changes into your life. Without transition, a change is just a rearrangement of the furniture. Unless transition happens, the change won't work, because it doesn't take.” -
William Bridges

> [Eur J Hum Genet.](#) 2019 Dec;27(12):1783-1790. doi: 10.1038/s41431-019-0460-z.
Epub 2019 Jul 30.

Current management of transition of young people affected by rare renal conditions in the ERKNet

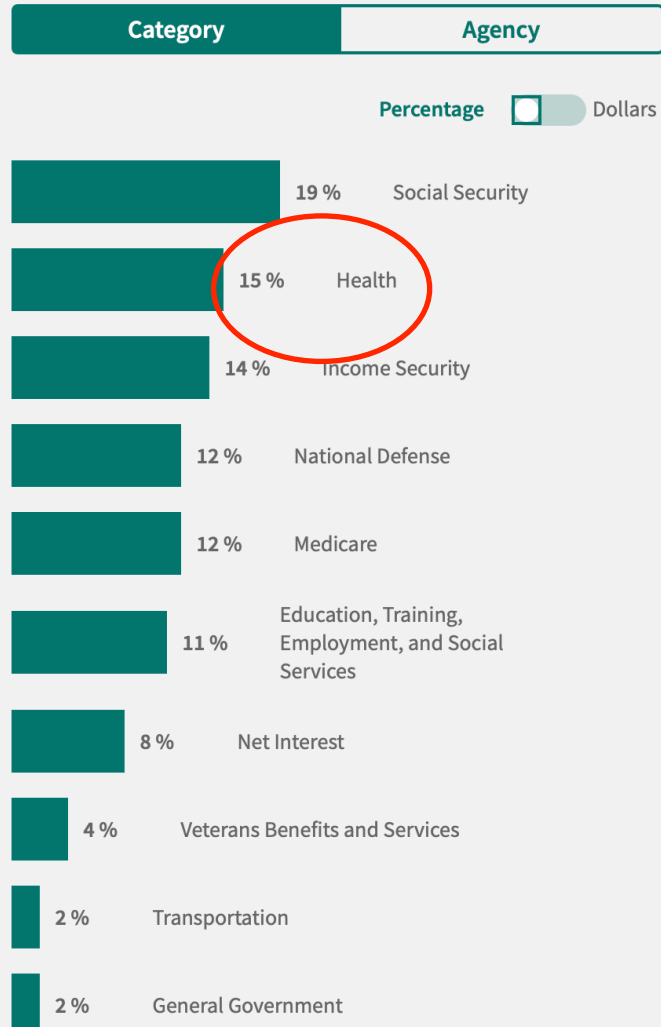
[Martin Kreuzer](#)¹, [Jens Drube](#)², [Jenny Prüfe](#)², [Franz Schaefer](#)³, [Lars Pape](#)²;
Members of the ERKNet Taskforce 'QoL & Transition'

‘Adherence to guidelines significantly correlated with gross national income’

What do Governments see?

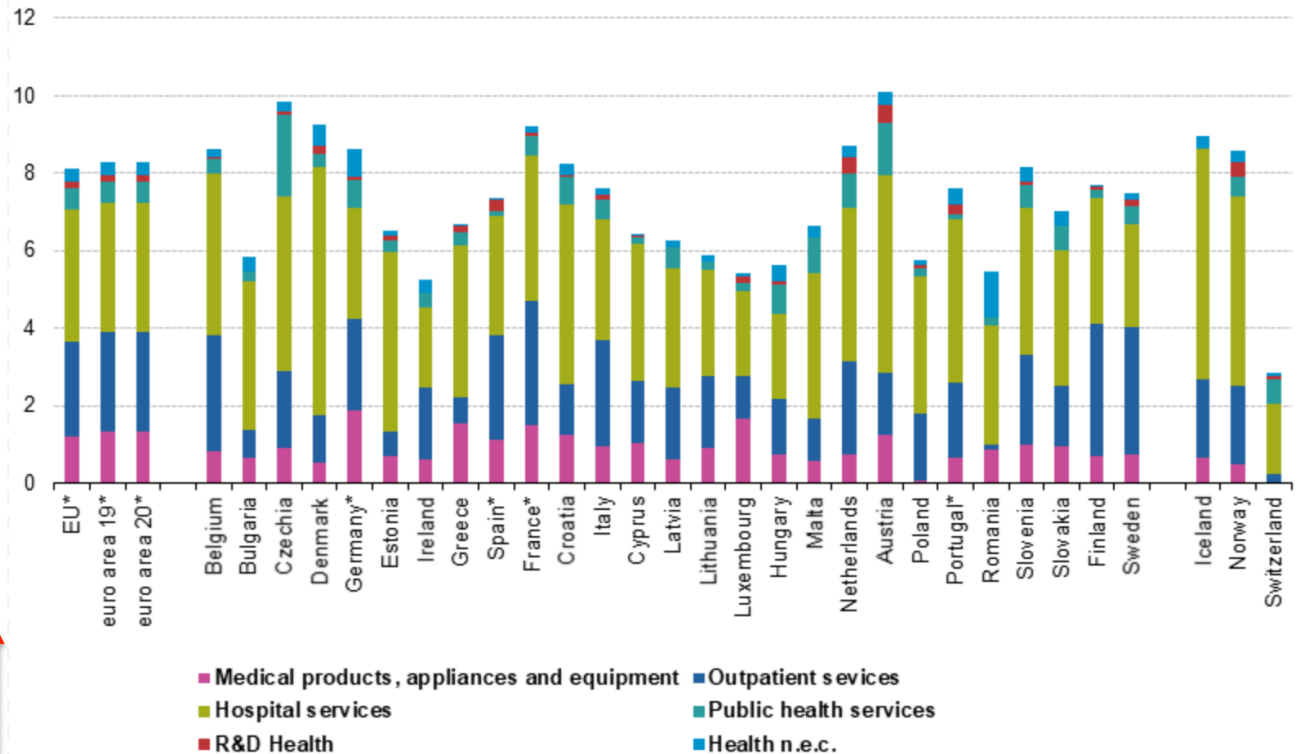
U.S. Government Spending, FY 2022

Top 10 Spending by Category and Agency



Children are essential investment for the future

Total general government expenditure on health, 2021 (% of GDP)



* provisional
Source: Eurostat (gov_10a_exp)

So far...

- Change is inevitable in life
- Children are experts in changing
- Fear of unknown is natural emotion
- Transition is a psychological process of self-redefinition
- Multi-disciplinary approach is essential
- Investment in transition programme is key

How?

In order to achieve to achieve positive results, one must work for them, not hope for them.

Bobby Knight

esot.org

Hope is not a strategy



'One finger can not lift a pebble' *Hopi proverb*

- Young person
- Family/friends/partners
- Play specialist, family therapist, psychologist, youth worker, school teacher, transition nurse +1
- Adult transplant team
 - nephrologist, clinical nurse specialist, transition nurse, surgeon, social worker, psychologist, Youth worker...

“Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has.” — Margaret Mead, American cultural anthropologist.

The John Hopkin Pediatric Solid Organ Transplant Transition Program

- Late childhood/early adolescence
- Close connection with adult transplant programmes
- Patient taking ownership
- Balance between patient needs/transplant programme resources

Figure 2: Lost to Follow-up Rates at 1 through 10 Years after Transplant for Kidney Transplants Performed during 2000 - 2010 by Age at Transplant²⁰

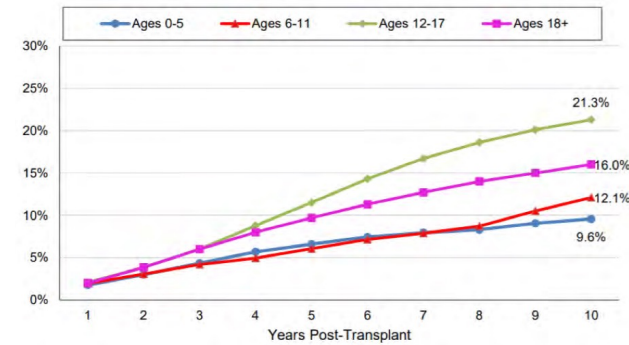
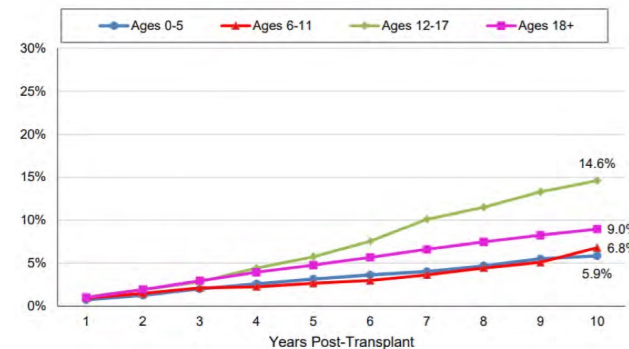


Figure 3: Lost to Follow-up at 1 through 10 Years after Transplant for Liver Transplants Performed during 2000 - 2010 by Age at Transplant²⁹



In each clinical visit:

- Transplant knowledge
- Medication knowledge
- Adherence to medication and lab work
- Understanding risk-taking behaviors
- How to stay healthy
- Self-advocacy
- Reproductive health
- Managing school and/or work
- Self-esteem
- Health insurance
- Advanced directives
- Identifying a support system

The Oxford Pediatric Solid Organ Transplant Transition Programme

- Lack of consistency in healthcare and support services
- Delivery of more patient-centred service
- Youth worker key
- Meetings not in hospital
 - Consider local coffee shops
- Integrated care
- Guideline but individualised programmes

> [Ann Saudi Med.](#) 2013 Sep-Oct;33(5):489-91. doi: 10.5144/0256-4947.2013.489.

Optimal management of young adult transplant recipients: the role of integrated multidisciplinary care and peer support

[Paul Neil Harden](#)¹, [Sam Nicholas Sherston](#)

Affiliations + expand

PMID: 24188944 PMID: [PMC6074886](#) DOI: [10.5144/0256-4947.2013.489](#)

[Practice Guideline](#) > [Kidney Int.](#) 2011 Oct;80(7):704-7. doi: 10.1038/ki.2011.209.

Epub 2011 Aug 10.

Transition from pediatric to adult renal services: a consensus statement by the International Society of Nephrology (ISN) and the International Pediatric Nephrology Association (IPNA)

[Alan R Watson](#)¹, [Paul N Harden](#), [Maria E Ferris](#), [Peter G Kerr](#), [John D Mahan](#), [Maher Fouad Ramzy](#); International Society of Nephrology; International Pediatric Nephrology Association

> [Arch Dis Child.](#) 2010 Aug;95(8):606-11. doi: 10.1136/adc.2009.176255. Epub 2010 Jun 1.

Building consensus on transition of transplant patients from paediatric to adult healthcare

[Nicholas Webb](#)¹, [Paul Harden](#), [Clive Lewis](#), [Sarah Tizzard](#), [Grainne Walsh](#), [Jo Wray](#), [Alan Watson](#)

Affiliations + expand

PMID: 20515964 DOI: [10.1136/adc.2009.176255](#)

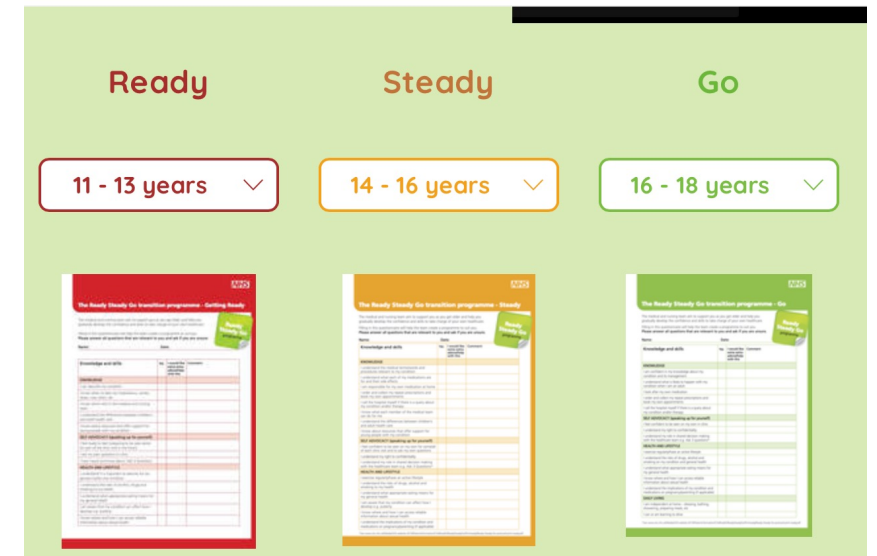
[esot.org](#)



Transition & Patient Empowerment, Innovation, Education & Research Collaboration



- Starts at 11 years of age
- Developed by clinicians at Southampton Children's Hospital, UK
- Long-term health condition
- Young person and family to gain skills and knowledge to manage condition into adulthood
- Empowering Young people
- Options
- Help in making choices



> [Arch Dis Child Educ Pract Ed](#). 2015 Dec;100(6):313-20. doi: 10.1136/archdischild-2014-307423. Epub 2015 Jun 10.

Implementing transition: Ready Steady Go

[Arvind Nagra](#)¹, [Patricia M McGinnity](#)², [Nikki Davis](#)³, [Anthony P Salmon](#)⁴

Affiliations + expand

PMID: 26063244 PMID: [PMC4680199](#) DOI: [10.1136/archdischild-2014-307423](#)

<https://www.readysteadygo.net/rsg.html>

Introduction

11 - 12 years



Ready

11 - 13 years



Steady

14 - 16 years



Go

16 - 18 years



Hello

First Adult Clinic



The Ready Steady Go transition program

The medical and nursing team aim to support you as you get older and gradually develop the confidence and skills to take charge of your own

Filling in this questionnaire will help the team create a programme to suit you. **Please answer all questions that are relevant to you and ask if you**

Name: _____ Date: _____

Knowledge and skills	Yes	I would like some extra advice/help with this
KNOWLEDGE		
I can describe my condition		
I know when to take my medications, names, doses, how often, etc		
I know who's who in the medical and nursing team		
I understand the differences between children's and adult health care		
I know about resources that offer support for young people with my condition		
SELF ADVOCACY (speaking up for yourself)		
I feel ready to start preparing to be seen alone for part of the clinic visit in the future		
I ask my own questions in clinic		
I have heard and know about 'Ask 3 Questions'		
HEALTH AND LIFESTYLE		
I understand it is important to exercise for my general health and condition		
I understand the risks of alcohol, drugs and smoking to my health		
I understand what appropriate eating means for my general health		
I am aware that my condition can affect how I develop e.g. puberty		
I know where and how I can access reliable information about sexual health		

The Ready Steady Go transition programme - Hello

The medical and nursing team aim to support and help you develop the confidence and skills to take charge of your own healthcare.

Filling in this questionnaire will help the team create a programme to suit you. **Please answer all questions that are relevant to you and ask if you are unsure.**

Name: _____ Date: _____

Knowledge and skills	Yes	I would like some extra advice/help with this	Comment
KNOWLEDGE			
I am confident in my knowledge about my condition and its management.			
I understand what is likely to happen with my condition in the future			
I understand what each of my medication/ treatment is for and their side effects			
I order and collect my repeat prescriptions and book my own appointments			
I know who to contact if I have any concerns about my health			
I call the hospital myself if there is a query about my condition or treatment			
I know about resources for young people or adults with my condition			
SELF ADVOCACY (speaking up for yourself)			
I feel confident to be seen on my own in clinic			
I understand my right to confidentiality			
I understand my role in shared decision making with the healthcare team e.g. Ask 3 Questions*			
HEALTH AND LIFESTYLE			
I exercise regularly/have an active lifestyle			
I understand the effect of smoking, drugs and alcohol on my condition and general health			
I understand what appropriate eating means for my general health			
I am aware that my condition can affect how I feel and function e.g. fatigue, sexual function, fertility			
I know where and how I can access providers for accurate information about sexual health			
I understand the implications of my condition and drugs on pregnancy/parenting			

*See leaflet or www.advancingqualityalliance.nhs.uk/wp-content/uploads/2013/04/BrochureFinal25.10.12.pdf



transition programme - Go

port you as you get older and help you s to take charge of your own healthcare.

am create a programme to suit you. **levant to you and ask if you are unsure.**

Name: _____ Date: _____

	Yes	I would like some extra advice/help with this	Comment
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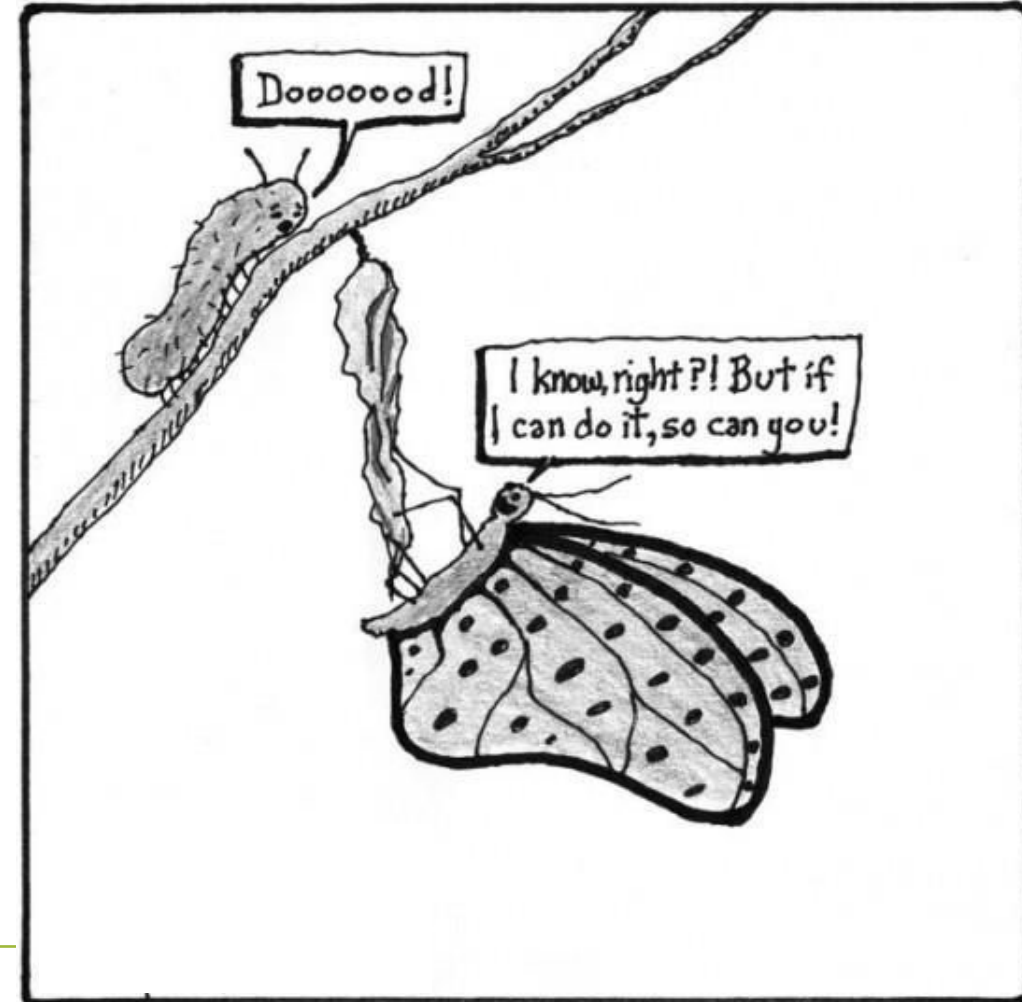
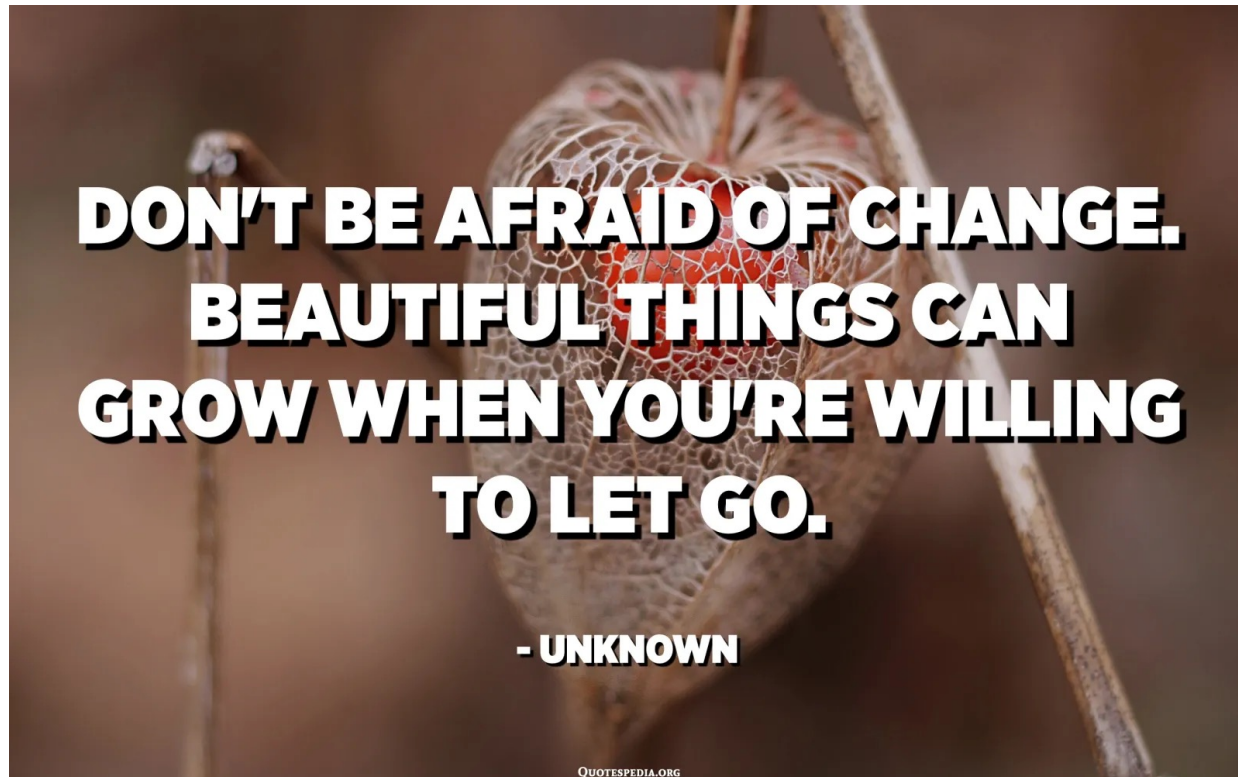
What do successful transplant programs have in common?

- Know that change is inevitable
- Fear is physiological emotion
- Transition is psychological process and is individual
- Focus on empowerment of young people
- Emphasis on community engagement and resources
 - Psychologist, social worker, family therapist
- Development of new friendships
 - Peer groups, Youth workers
- Help and support for the family

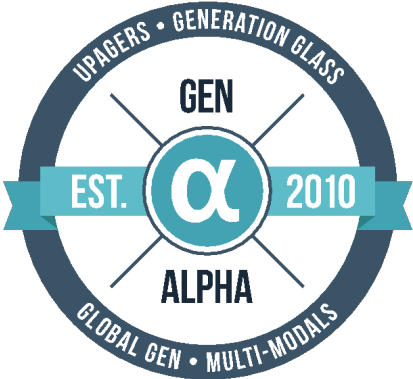


‘Behind every beautiful thing there is some pain’ *Bob Dylan*

Change is never painful, resistance to change is.
Uncertainty is painful for brain that wants to keep
us safe and alive.



Generation Alpha is coming: are you ready?



Nothing about me,
without me





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hospital for Children**

**Honorary Consultant at Kings College Hospital
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