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INDÉPENDANCE ET EXPERTISE POUR LE PROGRÈS DE LA SANTÉ À DOMICILE

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NONINVASIVE VENTILATION CONFERENCE

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Workshop:
Transition to adult care

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The child first and always

UCL INSTITUTE OF CHILD HEALTH

Great Ormond Street Hospital for Children NHS Foundation Trust

JA 17yo

- Diagnosis of nemaline rod congenital myopathy
- On BiPAP since the age of 12 with initial variable compliance but improved after significant input from NIV team, psychologist and play therapist
- BiPAP settings stable currently 18/6cmH2O with a back-up rate of 14 br/min
- Coming for last sleep study before “moving on” to adult services

Sleep study night

- Some concerns around the mask with pressure sore appearing on nasal bridge - addressed – new supply of siltape provided.
- Sleep study confirmed stability on current settings with no pressure change required
- SD card port from the ventilator dysfunctional – unable to download ventilator data but self-reporting good use
- Discharge from the sleep service with information that he will be referred to an adult NIV service but will stay under paediatric care until this process is completed (eg for consumables)

Any issues with this transition process?

What are the potential red flags?

Potential issues & red flags

- Previous issues requiring psychology and NIV team inputs
- Evidence of issues around the ventilator and its use (pressure sore – usb port) but open ended referral to adult care
- No previous introduction to adult NIV team
- Abruptness of the transition process without anyone being prepared beforehand

Presumptions about transition: what is true?

- Appropriate transition is an issue that is universal across conditions and countries
- Adolescent recognise and worry about the importance of the transition process
- Transition is done better for patients with normal neurocognition
- Transition should be done at or before 18 yo
- Transition is recognised as a public health priority due to the potential deleterious effects of poor transition

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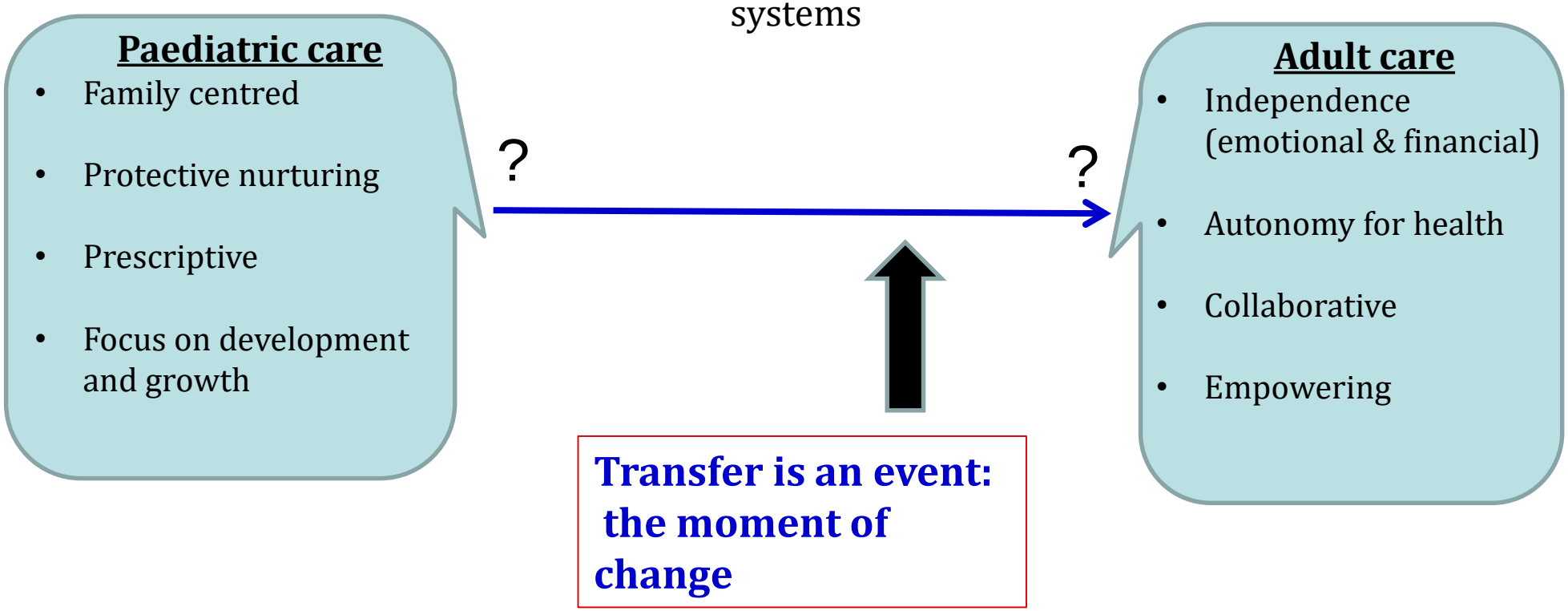
Transition is a process

The purposeful, planned movement of adolescents and young adults with chronic medical conditions from child-centred to adult –oriented health care systems



Players in successful transition

- Adolescents
- Parents
- Paediatric team
- Adult team

Parents concerns <> adolescent's concerns

Paediatrician concerns <> adult physician’s concerns

Paediatric teams concerns <> adolescents concerns

Transition to adult care: preparedness of the patient

- ***Gradual process*** , the rate of which varies from one individual to another, hopefully leading towards individual independence over a period of time.
- The transfer to adult care at 18 years of age is therefore relatively ***arbitrary***.
- The ***developmental stage (maturity)*** and ***ability for self-care*** by the patient, which may be impeded as a consequence of their underlying disease, is critical

Stam H et al. J Adolesc Health 2006 ; 39:4-83

Transition process

- Some patients are emotionally and intellectually mature while others may have difficulty assuming independent ***control and direction of their own care*** even well into adulthood
- ***Continuum***: transition should not occur at a specific age, but rather anywhere between 17 and 20 years of age, depending upon the level of preparedness of the patient

Cooley WC et al. Pediatrics 2011 ; 128:182-200

Transition process

- From early adolescence, ***developmentally appropriate care*** needs to be integrated into the child's care plan, allowing them to have an increasing role in their care, preparing them for the transition

- Adolescents, their families and healthcare providers must work together to develop a ***transition plan*** aimed at fostering ***health-promoting behaviours and adherence***

Table 1. Literature search results: Making the transition to adult care.

Author (Year)	Study type	# of pts.	Outcome 1	Outcome 2	Outcome 3	Outcome 4
McManus[30]	Survey (National) 2009–10 Families of Youth with Special Health Care Needs (YSHCN)	17,144	Only 40% surveyed met guidelines, with only 44% caregivers discussing transition/planning for transition to adult care	N/A	N/A	N/A
Reiss (2005)[24]	Qualitative (focus groups) individual YSHCN	143	N/A	Paucity of experienced caregivers/marked divergence in treatment approach	Little reported communication	N/A
Patel (2010)[15]	Survey pediatric and internal medicine residents	107	13.8% internal medicine residents received transition training, uncomfortable in caring for "adolescent" diseases	N/A	N/A	N/A
Stam (2006)[12]	Survey YSHCN patients	650 patients, 508 controls	Patients delayed milestones vs. controls	N/A	N/A	N/A
Pape (2013[31]	Comparative (nonrandom) adolescents post renal transplant transferred to 3 different adult care models	66	N/A	N/A	N/A	Specialized transition clinic had fewer changes in care, greater patient satisfaction compared to adult nephrologist or general transplantation clinic care
Oswald (2013)[32]	National survey of previously identified YSHCN	1,910 of 10,933 previously identified	N/A	N/A	N/A	Only 21.6% made successful transition. Those with successful transition more likely to report same or better health status.
Nakhla (2009)[20]	Longitudinal follow-up adolescents with diabetes mellitus until aged 20	1507	N/A	N/A	N/A	Increased risk of hospitalization vs. those ongoing follow up by current MD.

Outcome 1. Adequacy of education and preparedness for transition to adult healthcare.
Outcome 2. Availability of care/adequacy of receiving practitioner's knowledge and training.
Outcome 3. Adequacy of communication between pediatric and adult-orientated care.
Outcome 4. Impact of poor transition.

Maclusky I et al. Can J of Resp and Crit Care and Sleep Med 2018 ; 2:83-87

Transition to adult care: preparedness of the system

- Availability of knowledgeable healthcare providers:

In the tertiary centre

Children on home ventilation frequently suffer from diverse ailments which previously would have been fatal during childhood. Consequently, adult healthcare providers are **now assuming the care of a group of young adults who not only have needs outside of their usual experience, but also suffer from disorders with which they may have limited experience**[1].

1. *Patel MS et al. Pediatrics 2010 ; 126:s190-s193*

Transition to adult care: preparedness of the system

- Availability of knowledgeable healthcare providers:

In the community

- Children with complex, chronic care needs are often cared for in the community by paediatricians. Coincident with transfer to an adult program at a tertiary care center, there also is frequently a simultaneous ***transfer of community-based care to a general practitioner*** (if one can be found willing to take on the patient's general care[1]), adding to the family's stress, and ***risk of errors in transfer of information and loss of follow up***.

- Change in the availability of government-provided community support – new sets of rules and bureaucracy

1. *McLaughlin et al. J Pediatr Rehabil Med 2014 ; 7:63-70*

Transition to adult care: preparedness of the system

- Availability of technical resources

New technologies may be required in order achieve independence, with the patient and their caregivers faced with the task of identifying what is the most appropriate technology available to meet this goal, and how to obtain it within the new system

Transition to adult care: preparedness of the family

- Both the adolescent and their family need to be prepared for the transition.

- Parents of children on NIV are commonly required to be the primary advocates for their child's care. They are used to being major participants and having a primary role in the decision-making process for their child's care

Transition to adult care: preparedness of the family

- Difficulty in reducing parental involvement to allow the adolescent the degree of independent decision making and involvement in their care expected by most adult centres[1]

- Further compounded if the child has any degree of intellectual or motor limitations impeding their ability to assume this independence[2]

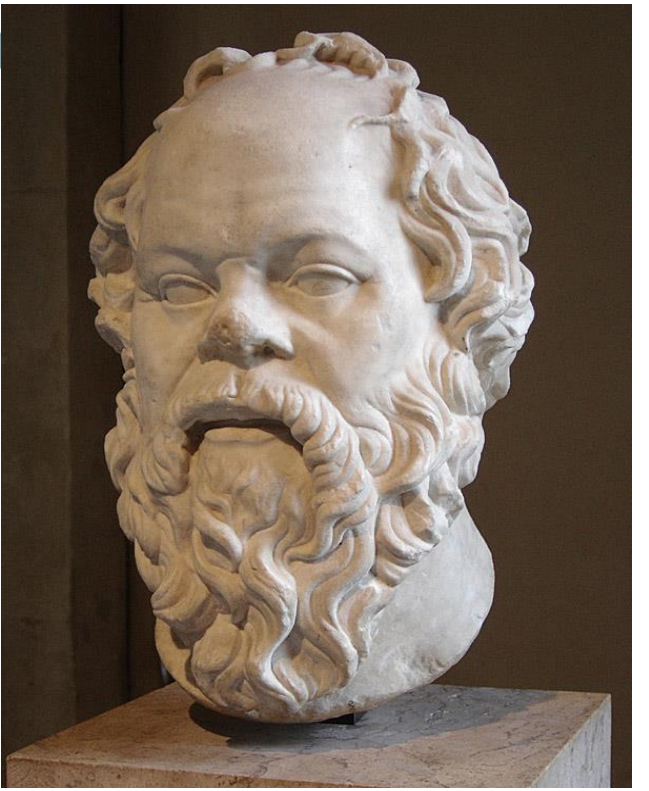
1. *Patel MS et al. Pediatrics 2010 ; 126:s190-s193*
2. *Davies H et al Can J Neurosci Nurs 2011;33(2):32–39*

Obstacles to successful transition

- Adolescents
- Parents
- Paediatric team
- Adult team

- Reluctant to leave
- Do not want to go to a unit of “crocks”
- Disengaged with process
- Moving to being old/dying
- Self perception as independent (indestructible)

The children now love luxury; they have bad manners, contempt for authority; they show disrespect for elders and love chatter in place of exercise. Children are now tyrants, not the servants of their households. They no longer rise when elders enter the room. They contradict their parents, chatter before company, gobble up dainties at the table, cross their legs, and tyrannize their teachers.



Socrates, Athens 480 BC

Obstacles to successful transition

- Adolescents
- Parents
- Paediatric team
- Adult team

- Reluctant to relinquish control
- Will be excluded
- Fear of unknown
- Reluctant to leave team that has kept the child well
- Infection risks

Obstacles to successful transition

- Adolescents
- Parents
- Paediatric team
- Adult team

- Reluctant to let go
- Interfering post transfer
- Too keen to hand them on!!
- Not participating in the shift towards the transition process
- Poor communication with the adult team

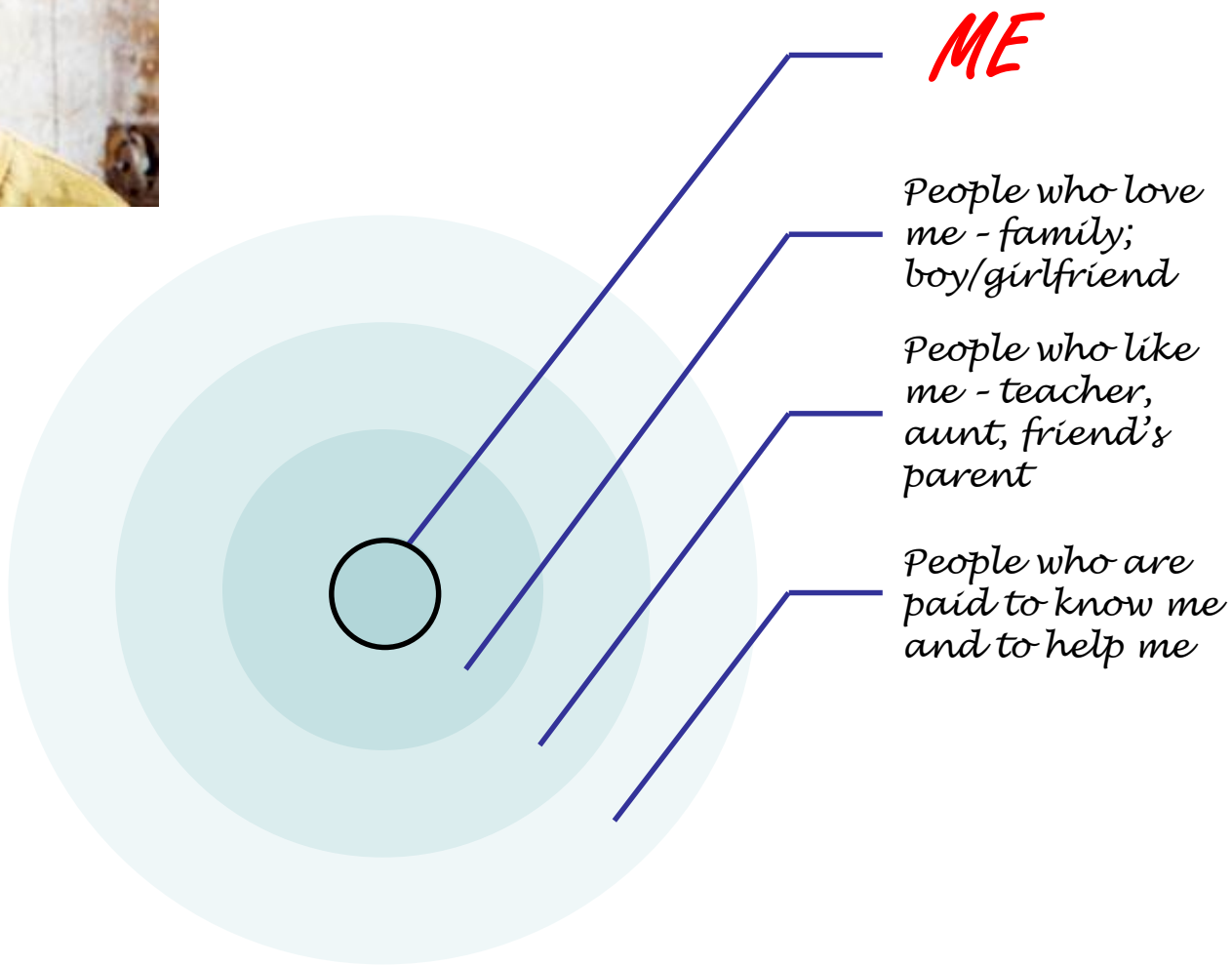
Obstacles to successful transition

- Adolescents
- Parents
- Paediatric team
- Adult team

- No knowledge or interest in “paediatric diseases”
- Limited resources
- Focus on the sick adults already within their practice
- Poor feedback post transfer with the paediatric teams
- No training in adolescent issues

What matters to you?

"One thing that must be recognised by those who work with adolescents is the fact that the adolescent boy or girl does not want to be understood" *Winnicott, 1965*


ME
People who love me - family; boy/girlfriend
People who like me - teacher, aunt, friend's parent
People who are paid to know me and to help me

Consequences of poorly carried out transition?

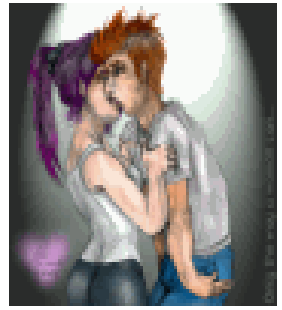
Consequences

- **Lack of adherence** to NIV with potential risk of deterioration of health status[1]
- **Deficiencies** in both knowledge about the condition and about follow-up, **leading to errors in self-care**[2-4]
- **Perceived deficiencies** in the care received in the adult-orientated healthcare setting (lack of knowledge – change in treatment)[5] with **loss of confidence** in new caregivers
- Limited **ability to direct personal care** necessary for ongoing health **in the adult health environment.** Patients may have both intellectual and physical/communication disabilities that limit their ability to "self-advocate" in order to ensure ongoing follow-up. This is associated with an increased risk of the patient being lost to follow-up

1. *Nakhla M et al. Pediatrics 2009 ; 124:e1834-e1841*
2. *Garvey KC et al. Diabetes Care 2012 ; 35:1716-22*
3. *Annunziato RA et al Pediatr Tranplant 2007 ; 11:608-14*
4. *Shemesh E et al. Curr Opin Organ Transplant 2010 ; 15:288-92*
5. *Reiss JG et al. Pediatrics 2005 ; 115:112-20*

The example of CF transition

- From ages 14-15yrs
- Over 2 year period
- Tackle adolescent issues
- Two Joint adolescent transition clinics (3 centres)
- Joint home visits, informal visits
- Parent support groups



Transition:
getting ready to move on to adult cystic fibrosis services

This information sheet explains a little about the transition process and what it will mean for you. Remember that if you have any questions about transition, please talk to your clinical nurse specialist, your consultant and/or your local Paediatrician.

Information for young people and families

Great Ormond Street Hospital for Children NHS Foundation Trust

How do I get ready to move on to the adult CF service?

When more formal discussions take place when you are around 14 years old, we will help you to prepare for your move.

Your parents have been really important in looking after your health and will be able to give you lots of helpful advice. They will have plenty of experience of things like taking you to the hospital, making appointments, asking questions and making sure you get your medicines or treatments. It is a good idea for you and your parents to talk about how moving to adult hospital makes you feel. You should make plans with them about how you can practise getting involved in looking after your health and taking responsibility. While you are preparing to move on, your parents will still be involved in your health care and still have an important role.

If you know any other young people that have already finished their transition, it might be useful to ask them for any tips on how to get ready. You could also ask them questions about the adult service.

It will be helpful for you to practise doing the following things to help prepare you for adult care.

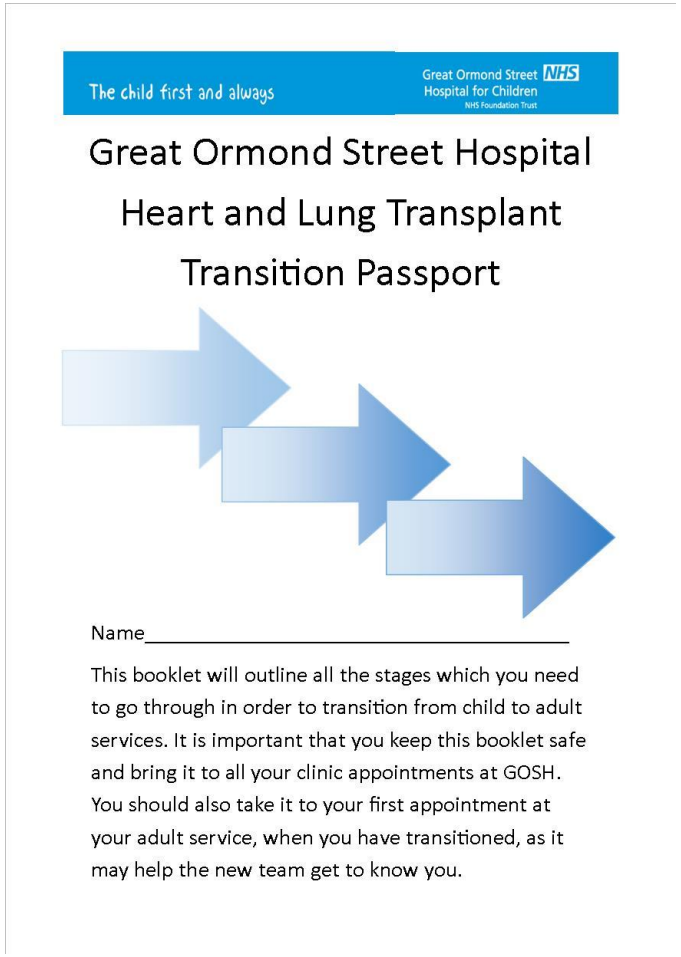
- learn about your conditions and treatments
- practise asking and answering questions during ward rounds and clinic appointments
- try to take some responsibility for remembering what your medicines are called, what they are for, how much to take and when to take them
- learn how to get more supplies of your medicines
- practise arranging appointments with your consultant, family doctor (GP), physiotherapist or dietician
- keep important phone numbers and appointment dates in your mobile phone, calendar or diary
- when you agree to treatment plans, make sure that you follow them properly
- try spending time without your parents for part of clinic appointments, then when you feel ready try spending the whole appointment on your own.

TRANSITION PATHWAY CHECKLIST

Timescale	Process	Date/By Whom	Signature
13-14yrs	Transition Discussion		
14yrs	Transition Information Letter Sent		
14yrs	Transition Clinic Choice	RBH / LC / Pap / All Other: (circle/add as appropriate)	
1st – 14yrs 2nd – 15yrs 3rd – 16yrs	Transition Clinics Attended	Date & Adult Centre 1st 2nd 3rd 4th	
14-15yrs	Informal Visit Discussed (include date of visit if known)		
15-16yrs	CNS Joint Home Visit (If required)		
15-16yrs	Final Adult Centre Choice		
16yrs	Planned Date for Transfer	Planned Date: Date discussed with pt/family:	
	Other Relevant Information		

A salutary lesson from our transplant unit

- Patients can be transplanted close to transfer date
- Care is often focused on immediate issues and a transition process to adult centres was at times hurried
- The relationship between the home team and the transplant team was not well co-ordinated
- Between 2009 and 2011 there were 8 deaths within one year of transfer
- An upgraded transition process was introduced with day long meetings of both teams and families 3X per year


The child first and always

Great Ormond Street Hospital for Children NHS

NHS Foundation Trust

Great Ormond Street Hospital

Heart and Lung Transplant

Transition Passport

Name_____

This booklet will outline all the stages which you need to go through in order to transition from child to adult services. It is important that you keep this booklet safe and bring it to all your clinic appointments at GOSH. You should also take it to your first appointment at your adult service, when you have transitioned, as it may help the new team get to know you.

Stage 1: Introducing Transition

Who has supported you through your transplant journey?

You might want to draw a family tree, as well as including friends, teachers or clinical team members who are important to you. Use your diagram to show who supports you at home and who supports you in other areas of life.

Do any of your family have similar or different health conditions? You might want to make a note of this on your family tree.

Stage 1: Introducing Transition

My Transplant Journey

Take some time with a parent or transplant Nurse to write about your transplant journey. You might like to start with why you needed a transplant, when you had one and what life has been like since. If there is anything you are unsure about this is a good time to ask questions.

Stage 1: Introducing Transition

Plans for my Transition

At each stage of transition you will have an opportunity to set yourself some goals to think about or act on before your next transition meeting. At this stage this might be:

- To learn more about your transplant journey
- To think about how you would like future clinic appointments to be

Things to do before we next meet:

-
-
-
-
-

Stage 2: Medication and Treatments

My Medications

It is important that you know what medications you take and what they are for. This is a good time to ask questions. Use the space below to list your current medications, current doses and their side effects.

Medication	Dose	Why I take it	Side Effects

Do you have any questions about your medications, their effects or side effects?

Stage 2: Medication and Treatments

Taking responsibility for medications

When you are seen in an adult centre you will be expected to take responsibility for managing your medications. As you get older and move away from home this will be essential. Therefore, we encourage young people to start to take responsibility for your medication.

How do you currently take your medication?

Does someone remind you? Do you get the doses ready? Do you always remember them? Do you always take them on time?

What ideas do you have for helping you remember to take your medications?

Use a dosset box

Keep a drug diary

Set a reminder on your phone

Stage 2: Medication and Treatments

Adherence to medication

What is medication adherence?

Why is it important?

What will happen if my adherence is not good?

Stage 2: Medication and Treatments

Prescriptions

As you approach 18 there might be some changes in the way you get your prescriptions. There will also be an expectation that you start to be more responsible for your prescriptions.

Changes in getting prescriptions?

How do I get a repeat prescription?

Who do I contact if I am running low on medication?

Stage 2: Medication and Treatments

Blood tests

Why do I have regular blood tests?

Where are the results sent?

What do the results mean?

Tacro -

FBC -

U & E's -

How do I arrange blood tests?

Stage 2: Medication and Treatments

Infection and Rejection in the Future

As you get older and take more responsibility for your health, it is important that you know how to look out for signs and symptoms of infection and rejection post-transplant.

What do you know about CMV?

What do you know about EBV?

Do you know the signs and symptoms of rejection?

Stage 2: Medication and Treatments

Plans for my Transition

At each stage of transition you will have an opportunity to set yourself some goals to think about or act on before your next transition meeting. For example at this stage these might be:

- To learn the names of all my medications
- To become more independent in taking medications
- To practice organising repeat prescriptions

Things to do before we next meet:

-
-
-
-

Stage 3: Meetings with the Team

Plans for my Transition

At each stage of transition you will have an opportunity to set yourself some goals to think about or act on before your next transition meeting. For example at this stage these might be:

- To arrange further psychology or physiotherapy appointments
- **********

Things to do before we next meet:

-
-
-
-

Stage 4: Taking Responsibility

Outpatient Appointment

At this clinic appointment we encourage you to be seen by the Doctor on your own for the first part of the appointment. If a parent or carer would also like to speak with the Doctor then you can decide to invite them to join the appointment part way through.

Stage 4: Taking Responsibility

It is important that everyone takes responsibility for looking after their own health. When you have had a transplant, part of this responsibility involves being aware of the additional risks that certain lifestyle choices have on your health and transplanted organ.

For the lifestyle choices below, fill in the risks and considerations which everyone should be aware of but may be particularly relevant if you have had had a transplant.

Drinking Alcohol

Smoking Cigarettes

Taking Drugs

Sex and Contraception

Stage 4: Taking Responsibility

Pregnancy & Menstrual Cycle

Driving

Piercings and Tattoos

Medical ID, Phones and Bracelets

Although following these guidelines is ideal, often people make decisions that is not in line with this advice. If this happens it is important to talk to or inform your medical team of these decisions so they can take them into account in your treatment. You won't be told off, but part of becoming an adult and independent with your own care is to take responsibility for your decisions.

Stage 4: Taking Responsibility

Plans for the future

This booklet is helping you to prepare for transition to adult healthcare services. However, we are also aware that at this stage of your life you might be planning for lots of other transitions, such as leaving school or moving house.

Use the boxes below to write down your plans for transition in other areas of your life over the next few years.

Education

Work

Accommodation

Important! - If you are moving you need to register with a new GP

Stage 4: Taking Responsibility

Annual Review

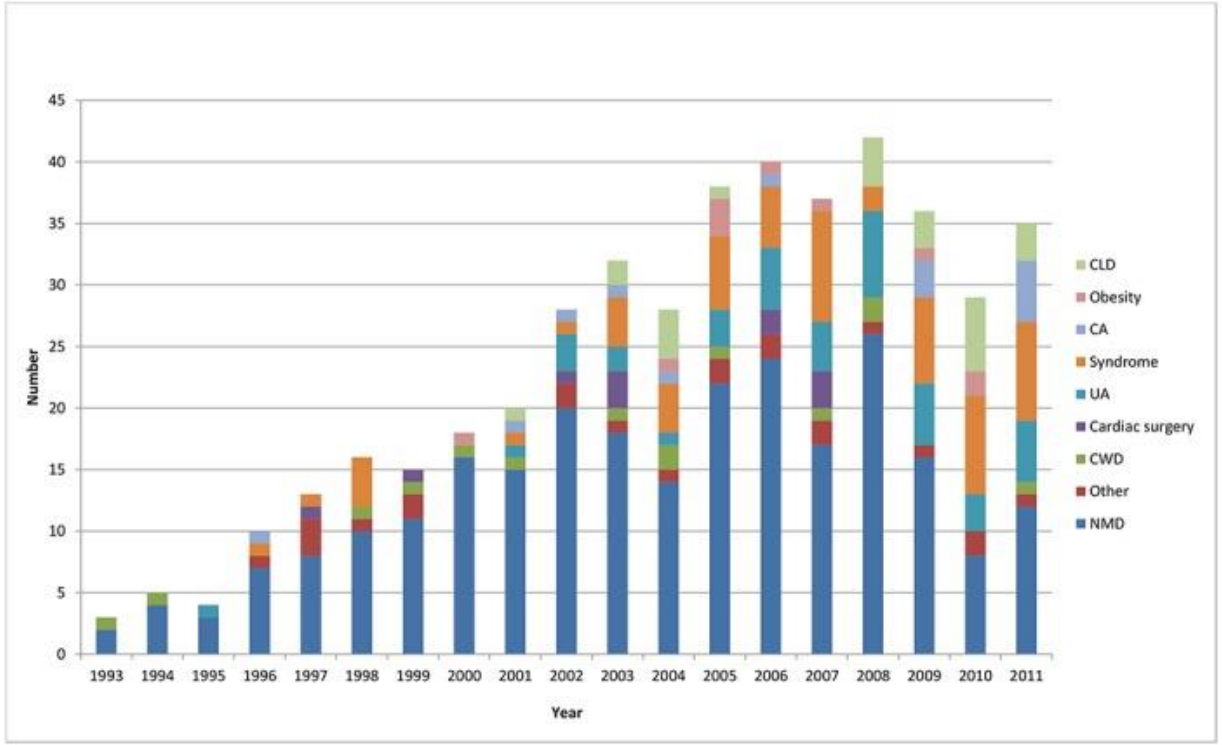
As you will probably be aware the annual review you have post transplant usually involves a procedure under general anaesthetic.

All of the adult transplant centres in the UK complete the annual review under local rather than general anaesthetic. We suggest that young people approaching transition choose to have their final annual review at GOSH conducted under local anaesthetic so they get used to this process while being in a familiar environment with familiar clinicians.

This is an opportunity to think about this and write down below any worries or questions:

Consider these respiratory conditions:

- Approx 600 children on NIV
- Approx 150 children on tracheostomy ventilation
- Survivors of previously lethal conditions – ILD; Gauchers; Pompe's
- Cerebral palsy & aspirators
- CCHS
- SWAN's



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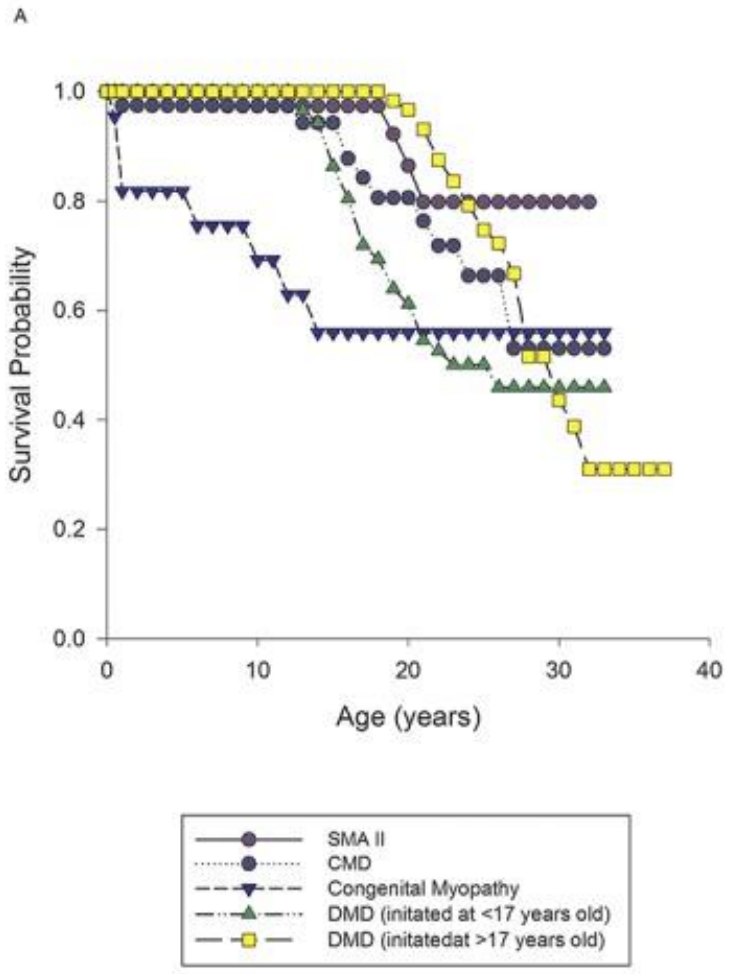

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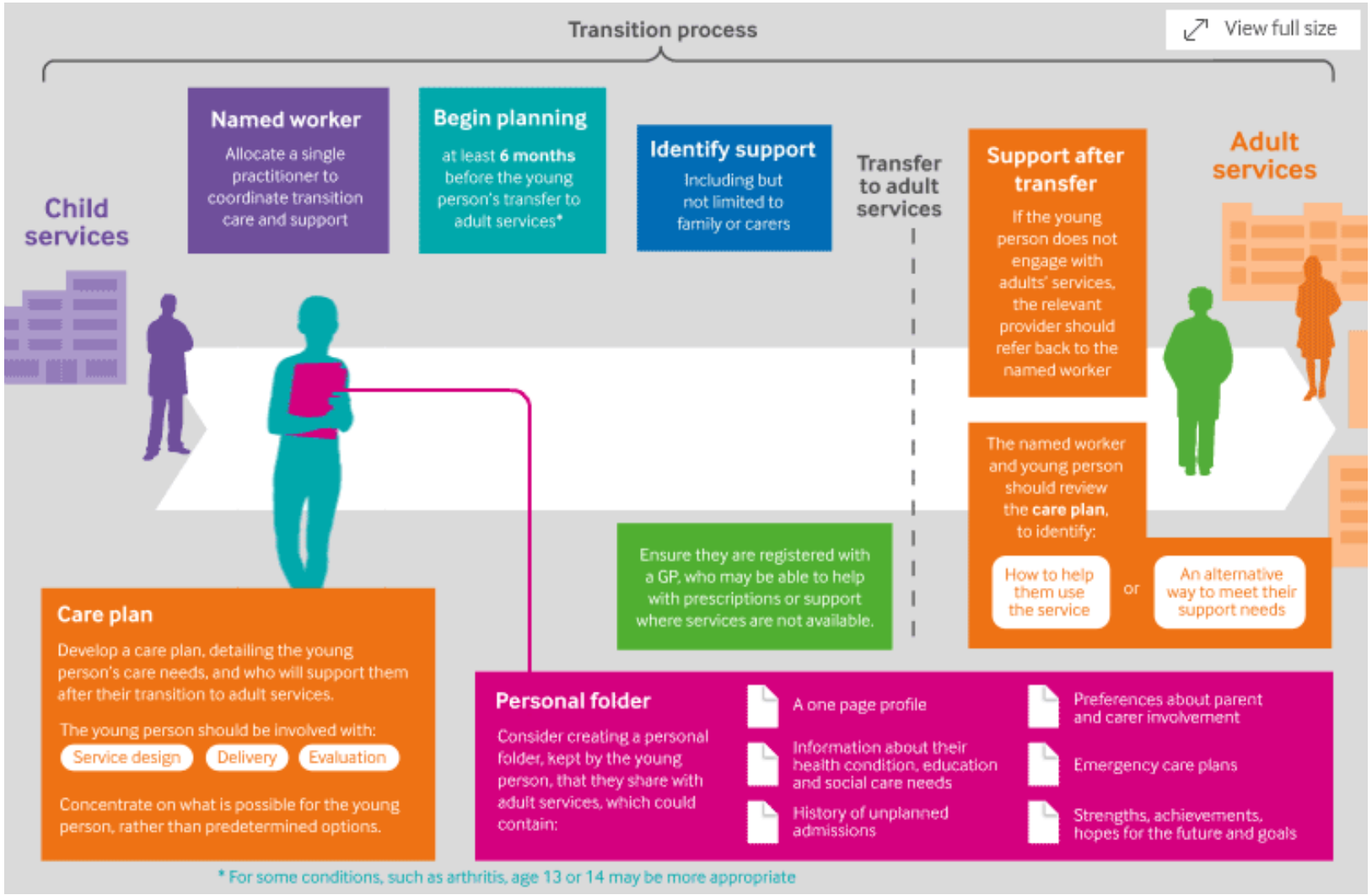
- SWAN's

Are we transferring at the right time?



Transfer must be a positive step

To Paediatric Teams

- Don't transfer patient if end stage disease
- Don’t prevent the dignity of making informed “adult” decisions
- Beware of transferring in the middle of psychosocial turmoil
- Apprehension is not a reason to delay transfer
- Remember the young person may be able to establish a more equitable relationship with the adult team

To Adult Teams

- Make a good impression on your first date
- Don’t overwhelm at the beginning
- Don’t criticise the paediatric team – directly or indirectly
- Don’t change everything on the first date
- Take time to learn about the individual – even if they appear very well
- Stress the positives of transfer

Thank you for you attention

Any questions?

francois.abel@gosh.nhs.uk

Great Ormond Street Hospital for Children NHS Foundation Trust