



Duchenne Muscular Dystrophy: Palliative Management and Transition to Adult Services

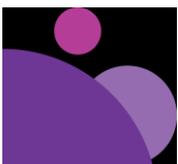
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Consultant in Paediatric Palliative Care (Oxford)
Medical Director Helen & Douglas House

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Introduction



- Current Management of Duchenne Muscular Dystrophy
- Referral to Paediatric / Adolescent Palliative & Supportive Care
- Long Term Ventilation & difficult decisions
- Transition to adult services
- Voices of the Young People



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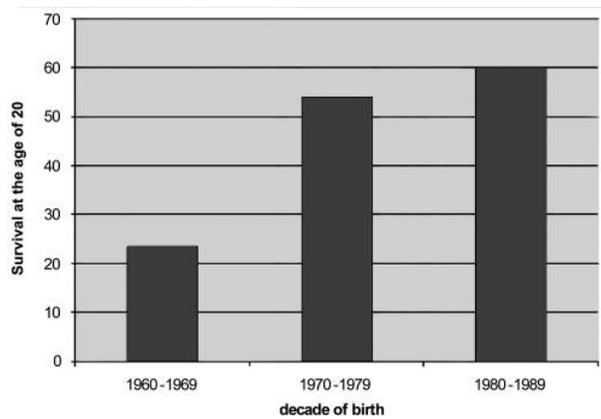
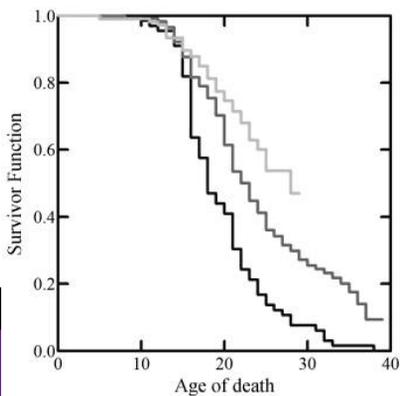
Disease & Current Management



Survival Improvement

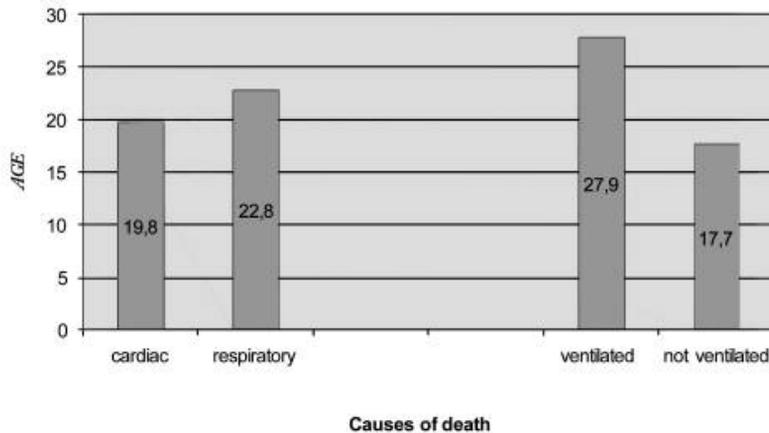


Survival Plot



Cause of Death

Causes of death in DMD patients. On the left the mean age for cardiac or respiratory causes is reported; on the right the mean age of death in ventilated versus non-ventilated patients.



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Typical Current Treatment

- **Corticosteroids** – delays loss of walking but has significant side effects; growth retardation, bone thinning, mood swings and weight gain
- **Cardiac monitoring** – regular ECHOs and early ACE inhibitors (annual review)
- **Respiratory monitoring** – Sleep studies annually, early nocturnal NIV
- **Spinal Surgery** – to maintain seated position and improve respiratory effort
- **Gastrostomy** – to support optimal nutrition
- **Bone fragility management** – non-weight bearing, steroid use, less time outdoors - important to avoid pathological fractures

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New & Emerging Treatments

- **Disease modifying Treatment: Ataluren (*Translarna*)**
 - NICE have made this available to boys over 5 years who can still walk and have a nonsense mutation in the dystrophin gene (since 2016).
 - Restores synthesis of dystrophin by allowing ribosomes to read through premature stop codons
 - Typical cost >£200,000 per year – clinical benefit ‘moderate’
 - <https://www.nice.org.uk/news/article/nice-publishes-final-guidance-recommending-ataluren-for-children-with-duchenne-muscular-dystrophy>
- **Gene Therapy Potential**
 - Dystrophin is a huge gene and difficult to insert in to a viral vector.
 - Microdystrophin has been developed and can produce a shortened but effective dystrophin protein in research settings / early phase trials
 - <https://muscular dystrophy news.com/2018/06/22/microdystrophin-gene-therapy-shows-promise-early-trial-results/>



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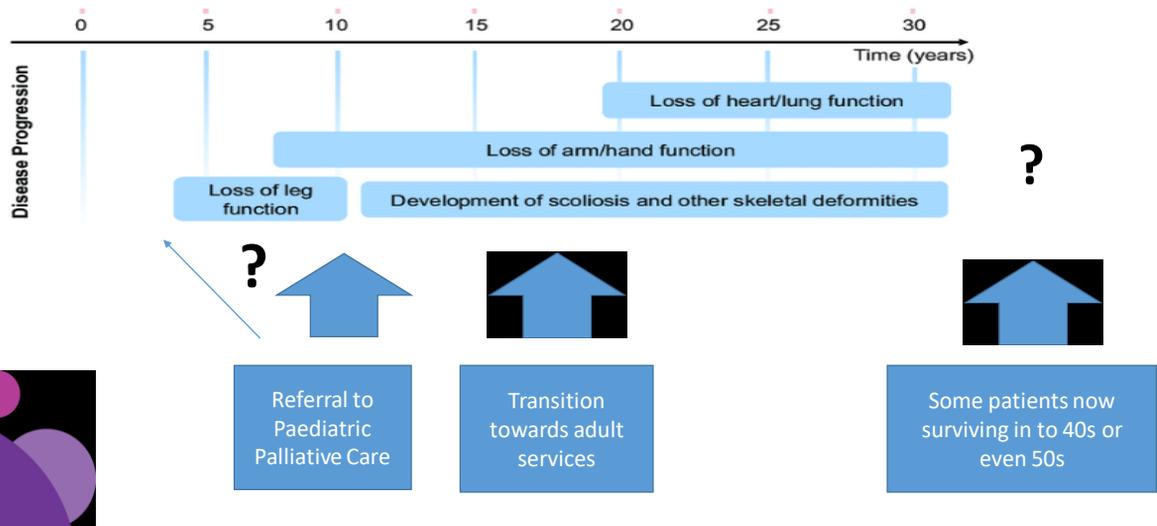
Referral to Palliative Care



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Typical Disease Progression



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Children's Hospices



- DMD patients 17% of the UK Children's Hospice population
- >70% of admissions are planned for respite or medical review
- In Thames Valley, commonest age at referral 10-12yrs
 - Half were on NIV at referral
 - 1/3 had had spinal surgery
 - 36% were on cardiac medication
 - 15% had had PICU admissions
- Triggers to referral were more to do with disease progression than PICU admissions

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Children's Hospices



- Younger, mobile patients ? 'harmed' by hospice environment?
- Negative impact on aspirations?
- Despite this many patients are 'frail' in adolescence and need to be identified
- Helen & Douglas House have recently been working on a traffic lights based tool
 - Children who are 'green or 'yellow': social events, youth work, family support
 - Children who are 'amber' or 'red': respite in House, ACPs, stepped discharges, and maybe end of life care

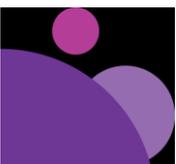


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Motor Function



- Stable motor function
- Worsening / unsafe gait
- Manual wheelchair in use several times a week
- Electric wheelchair user

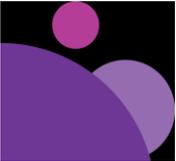


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Spinal Deformity



- Mild scoliosis
- Moderate scoliosis pre-surgery
- Spinal surgery (time around planned surgery may be a good time to refer)
- Surgery declined due to other vulnerabilities

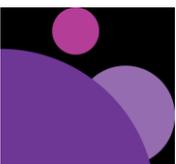


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Cardiac Compromise



- Normal ECHO – annual review only
- ACE inhibitor therapy for treatment rather than prophylaxis
- Second line cardiac medication added
- Significant reduction in left ventricular ejection fraction



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Respiratory Function



- No symptoms of hypoventilation, no prolonged chesty illnesses, and effective cough
- Prolonged chesty episodes treated at home
- Hospital admissions for chesty episodes
- Adjuncts for secretion management used: Lung Volume Recruitment Bag / Mechanical Insufflation-Insufflation (Cough Assist) device
- Non-invasive ventilation at night
- Non-invasive ventilation for increasing hours of the day
- Dependent on 24hr non-invasive ventilation
- Tracheostomy ventilation

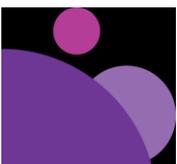


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Weight / Nutrition



- Able to eat & drink unassisted, no concerns about safety of swallow, normal height & weight for age
- Weight >90th centile or <10th centile for age
- Dependent on enteral tube feeding (including overnight)
- Signs of gut dysfunction affecting nutritional status



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Paediatric Critical Care



- No critical care stays
- Elective admission for planned intervention prolonged by complications
- Unplanned admission
- Multiple / prolonged unplanned admissions



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References for the tool



1. **Duchenne Muscular Dystrophy: Patterns of Clinical Progression and effects of supportive therapy.** Brooke M et al (1989) Neurology 39(4):475-81
2. **Profiles of Neuromuscular Disease. Duchenne Muscular Dystrophy.** Mc Donald et al (1995) Am J Phys Med Rehabil 74(5 suppl): S70-92
3. **Survival of Patients with Duchenne Muscular Dystrophy.** San Martin P, Solis F & Cavada G (2018) Rev Chil Pediatr 89(4):477-483
4. **Update on the Management of Duchenne Muscular Dystrophy.** Manzur AY, Kinali M & Muntoni F (2007) Arch Dis Child
5. **Disability and Survival in Duchenne Muscular Dystrophy.** Kohler M et al (2009) J Neurol Neurosurg 80(3): 320-325
6. **Managing Duchenne Muscular Dystrophy: The Additive Effect of Spinal Surgery and Home Nocturnal Ventilation in Improving Survival.** Eagle M, Bourke J, Bullock R, Gibson M, Mehtaa J, Giddings D et al.(2007) Neuromuscular Disorders 17: 470-475.
7. **Hospice provision and usage amongst young people with neuromuscular disease in the United Kingdom.** Fraser LK, Aldridge J, King S, O'Leary S, Miller M, McCulloch R et al (2011) European Journal of Paediatric Neurology 15: 326-30.



The tool was also peer reviewed by Dr Jeremy Hull, Prof Anita Simmonds, Hayley Ramjattan, Dr Alison Shefler, Dr Sithar Ramdas, Dr Alex Jones, Prof Laurent Servias, and the Helen House referral team

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LTV & Difficult Decisions



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Long Term Ventilation

Long-term ventilation (LTV) is considered as *mechanical support for breathing in a medically stable patient, regardless of interface, for all or part of the 24-hour day*

- The use of long-term ventilation is growing in the UK almost exponentially
- Cost effectiveness to the NHS has NOT been assessed by NICE
- Burdens < benefits when used as a 'bridge to recovery'
- Less clear when likely to be 'destination therapy'
- Long-term ventilation DOES improve survival in progressive conditions such as neuromuscular disease – but at what cost, and where is the 'ceiling of treatment'?

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Towards developing an ethical framework for decision making in long-term ventilation in children

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ABSTRACT

The use of long-term ventilation (LTV) in children is growing in the UK and worldwide. This reflects the improvement in technology to provide LTV, the growing number of indications in which it can be successfully delivered and the acceptability of LTV to families and children. In this article, we discuss the various considerations to be made when deciding to initiate or continue LTV, describe the process that *should* be followed, as decided by a consensus of experienced physicians, and outline the options available for resolution of conflict around LTV decision making. We recognise the uncertainty and hope provided by novel and evolving therapies for potential disease modification. This raises the question of whether LTV should be offered to allow time for a therapy to be trialled, or whether the therapy is so unlikely to be effective, LTV would simply prolong suffering. We put this consensus view forward as an ethical framework for decision making in children requiring LTV.

What is already known?

- ▶ The number of children needing long-term ventilation is increasing.
- ▶ Decision making in long-term ventilation is made on a case-by-case basis, but no standardised framework exists.

What this study adds?

- ▶ Standardised processes with multidisciplinary involvement are likely to improve the consistency and quality of decision making in long-term ventilation.
- ▶ Novel therapies introduce uncertainty into decision making in long-term ventilation.
- ▶ Parallel planning must be undertaken alongside providing long-term ventilation.

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Specific Considerations



Box 1 Specific considerations regarding decision making in long-term ventilation (LTV)

- ▶ LTV is provided for a wide, and ever increasing, range of conditions. For many of these indications, the outcome of LTV has not been evaluated, is uncertain or is unknown.
- ▶ LTV is never a curative intervention; it cannot alter static or progressive conditions or the risks and burdens of comorbidities.
- ▶ In some cases, LTV is a 'bridge' to definitive therapy or recovery following growth. However, in many circumstances, LTV is a 'destination' therapy. Goals of treatment can change over time and need repeated re-evaluation.
- ▶ LTV is by definition 'long term'. Dependency on a ventilator can become part of life, rather than a treatment that can be withdrawn. This may occur without re-evaluation of the changing balance between benefits and burdens.
- ▶ Although portable ventilators have been available for over 30 years, the relative low numbers of long-term ventilated children means that expertise is still concentrated in tertiary centres, and care needs still involve specialist skills. This can introduce unforeseen burdens beyond the direct effects of attaching a ventilator to a child, such as prolonged stay in hospital and intensive care environments, which may retard development.
- ▶ Emerging or experimental treatments provide hope for a cure, which may often be unrealistic. LTV may be sought for a child as a bridge to potential cure. However, the likelihood of a successful cure has to be reviewed regularly, along with treatment burdens.

- Need for regular airway **suction** – distressing?
- Discomfort related to ventilator **asynchrony**
- Complications related to the **tracheostomy site**
- Possibility of a '**locked in state**' with no motor activity
- Stays in hospital of 9-12 months minimum
- Inability to fill **care packages**

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Shared Decision Making



Box 4 Good practice in shared decision making

- ▶ Decision making is a process, and decisions should not be made in a single meeting.
- ▶ Combine the clinician's knowledge and experience with the understanding, values, beliefs and expectations of the child and parent(s) to achieve optimal outcomes for the child.
- ▶ Communication between these stakeholders must be open, empathetic and non-judgemental.
- ▶ Initial discussions must centre around obtaining relevant information and discuss diagnosis, prognosis and, crucially, the goals of care—what will success look like?
- ▶ It is important to assess the family's current understanding and perceptions concerning the illness and the treatment options.
- ▶ It is paramount that the family feel that the healthcare team empathise with them and their child, acknowledging the difficulty in the decision making.
- ▶ Physicians should present an honest account of what life entails for a family caring for a child on LTV. Where possible, families should be given an opportunity to contact other families with children on LTV. This may be done through video diaries or remotely, but ideally should attempt to give a realistic perspective of local services available. However, with variation in underlying pathology, dependency and outcome, difficulties can arise in managing expectations appropriately.

- A **process**, not a single meeting
- Clinician **knowledge** dovetailed with family **values, beliefs, and expectations**
- Open, **non-judgemental** communication
- 'What could success look like?'
- What would be a worst case scenario?
- Acknowledge the difficulty of the decision
- **Honest account** of what life is like with LTV

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How do families feel at home?



Training and preparation of family carers who carry out complex healthcare procedures in the home

Ethics Approval Reference: R55580/RE001



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Analysis of paediatric long-term ventilation incidents in the community

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ABSTRACT

Aim To describe the nature and causes of reported patient safety incidents relating to care in the community for children dependent on long-term ventilation with the further aim of improving safety.

Methods We undertook an analysis of patient safety incident data relating to long-term ventilation in the community using incident reports from England and Wales' National Reporting and Learning System occurring between January 2013 and December 2017. Manual screening by two authors identified 220 incidents which met the inclusion criteria. The free text for each report was descriptively analysed to identify the problems in the delivery of care, the contributory factors and the patient outcome.

Results Common problems in the delivery of care included issues with faulty equipment and the availability of equipment, and concerns around staff competency. There was a clearly stated harm to the child in 89 incidents (40%). Contributory factors included staff shortages, out of hours care, and issues with packaging and instructions for equipment.

Conclusions This study identifies a range of problems relating to long-term ventilation in the community, some of which raise serious safety concerns. The provision of services to support children on long-term ventilation and their families needs to improve. Priorities include training of staff, maintenance and availability of equipment, support for families and coordination of care.

What is already known on this topic

- ▶ The number of children on long-term ventilation cared for at home is rapidly increasing.
- ▶ There are significant risks in long-term ventilation that need to be carefully managed.
- ▶ Little is known about the safety of care for children on long-term ventilation in the community.

What this study adds

- ▶ This study identifies a range of problems in care and underlying factors experienced by children on long-term ventilation at home.
- ▶ Priorities for improvement are training of staff, maintenance and availability of equipment, support for families and improving coordination of care.

Support for families on long-term ventilation care

Children on long-term ventilation need an extensive care package to provide long-term medical, nursing and physiotherapy support.⁴ Common

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NRLS Incident report analysis

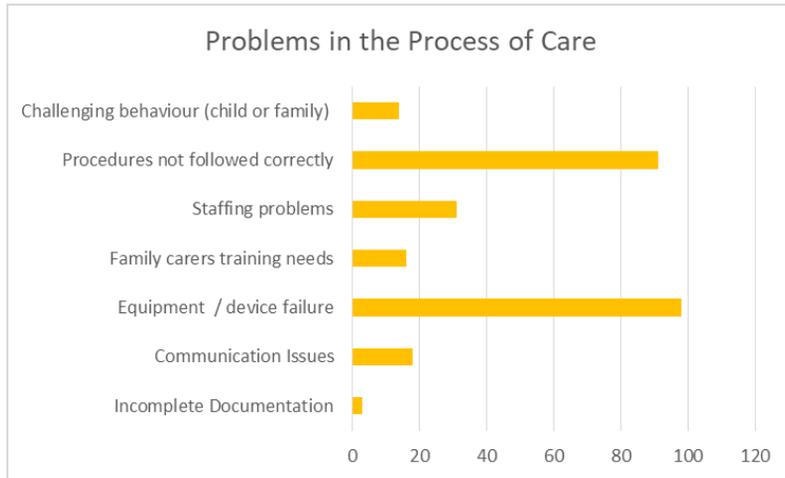


- National Reporting & Learning System (NRLS) – repository of patient safety incidents from NHS organisations in England and Wales (NHS Improvement)
- 217 **paediatric community incidents** between Jan 2013-Dec 2017 (4015 including inpatients)
- Clear themes identified and used to guide the work within AHSN
- Significant numbers of incidents resulting in **actual harm**



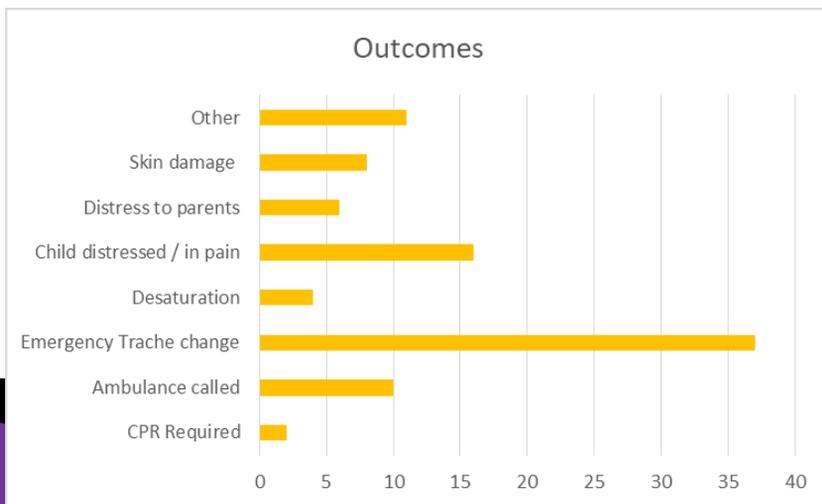
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Identified Themes



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Harmful Outcomes



87 cases of clearly stated harm
118 potential harm



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Transition to Adult Services



Chronic Illness in Adolescence



Chronic illness or disability and adolescent development

EFFECTS OF ILLNESS ON DEVELOPMENT	EFFECTS OF DEVELOPMENTAL ISSUES ON ILLNESS OR DISABILITY
<p>Biological</p> <ul style="list-style-type: none"> → Delayed puberty. → Short stature. → Reduced bone mass accretion. 	<p>Biological</p> <ul style="list-style-type: none"> → Increased caloric requirement for growth may negatively impact on disease parameters. → Pubertal hormones may impact upon disease parameters.
<p>Psychological</p> <ul style="list-style-type: none"> → Regressive behaviour. → Adoption of sick role as personal identifier. → Egocentricity persists into late adolescence. → Impaired development of sense of sexual or attractive self. 	<p>Poor adherence and poor disease control due to:</p> <ul style="list-style-type: none"> → Poorly developed abstract thinking and planning (reduced ability to plan and prepare using abstract concepts). → Difficulty in imagining the future; self-concept as being 'bullet-proof'. → Exploratory (risk-taking) behaviour.
<p>Social</p> <ul style="list-style-type: none"> → Reduced independence at a time when independence is normally developing. → Difficulties in peer relationships. → Creating new intimate (couple) relationships. → Social isolation. → Educational failure and then vocational failure; failure of development of independent living ability. 	<p>Associated health risk behaviours</p> <ul style="list-style-type: none"> → Chaotic eating habits may result in poor nutrition. → Smoking, alcohol and drug use often in excess of normal population rates. → Sexual risk-taking, possibly in view of realization of limited life span.



Key Differences from Paediatrics



Moving into adult services is like going from a pond into the sea.

Young adults are not big children, but nor are we little adults. We need to start caring for young adults in a way that treats us as a unique subgroup with defined needs, wishes, goals and experiences.



Lucy Watts MBE



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So how should Transition look?



It's important that we as young adults (where able) must step up but our parent(s) must be able to allow us to take control and make our own decisions - even if the parent doesn't agree with them. This includes making mistakes, within reason.

Transition is a learning curve for both young person and their parent(s)/family.

There is no one-size-fits-all transition policy. You can't implement a policy that treats each young person, each family, each case the same way.

You must have a policy for transition, but there needs to be the ability to adapt or personalise that policy for each case, to get the best out of the transition for the young person and their family.

Transition care planning is vital and that plan must also incorporate the family and their needs, so that professionals can not only support the young adult, but can support the family effectively, too.



Lucy Watts MBE

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What about Parents?

My full transition to adulthood occurred when mum was diagnosed with a brain tumour, and then suffered a brain haemorrhage and a stroke after the operation.

Suddenly she wasn't there to do all the liaising, organising, phone calls, finances and so on and I had to take this on myself.

When she recovered, mum found I wasn't the same daughter she had pre-op. I was more confident, in control of my life, doing everything like organising, liaising, finances and so on for myself. Mum has had to learn to step back, which she has found hard, and we've had to work out a new relationship in many ways, to find our new normal.

Lucy Watts MBE

It cannot be underestimated the impact on the parents of having to learn to take a back seat.

The added vulnerability of the young person by nature of their life-limiting illness or disability makes it even harder for parents to step back, as they have an added need to protect their child.



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Our 'bereavement'

Douglas House 2004-2018 RIP



- Medically supported short breaks
- Opportunities: Festivals, sports matches, night clubbing, parties in House
- Symptom Management
- Care Coordination
- End of Life care

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Helen & Douglas House Toolkit



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'Elaine is now 19 years old and going through her transition was horrible; it was the worst experience of our lives. Our daughter was entitled to home care. It was difficult trying to get professionals to talk to Elaine as an adult in her own right and not as my child.'
Mother, July 2013

- Toolkit drawing on the first decade of experience running Douglas House



<https://www.helenanddouglas.org.uk/wp-content/uploads/2018/01/hdh-transition-and-beyond-toolkit.pdf>

Age Appropriate Environment



ENVIRONMENTS

1. Personalisation of the environment. Young people can bring in personal items such as pillows, throws and photographs to individualise their bed area.
2. Use of mobile phones and/or laptops, which are often 'lifelines' to peers and family.

3. Flexible visiting times, including overnight stays where possible, to enable peer and family visiting.
4. Age-related routines. For example, going to bed later, waking later, eating at different times of the day.
5. Age appropriate recreational activities e.g. internet access (with appropriate regulations and restrictions), games consoles, pool tables.
6. Co-location of young people with people of a similar age range.

'I think about my passing a lot...I've done it all my life...I haven't spoken about it much with anybody else...it's not the sort of thing I can say to my family. They say, "why do you have to go on about it?"'
MD, age 22



Sexuality



Sexuality is widely recognised as complex and multidimensional.

Definitions can include the following aspects:

- | | |
|---|--|
| <ol style="list-style-type: none"> 1. Self esteem. 2. Self-identity. 3. Acceptance of body image. 4. Comfort with gender identity. 5. Need for touch. 6. Interest in sexual activity. | <ol style="list-style-type: none"> 7. Ability to communicate sexual needs. 8. Expression of caring. 9. Giving and receiving of pleasure 10. Ability to engage in satisfying sexual activity. |
|---|--|

Sexuality link role – possible strategies for developing this role within your organisation:

- Gather a bank of useful resources, including articles of interest, information about local facilities (sexual health clinics, dating agencies), useful websites and books.
- Network with external agencies, local and national, to establish the expertise that exists in this area, and how you can use this within your work environment.
- Form a sexuality group working party to lead on supporting the team with issues relating to sexuality.
- Develop a sexuality policy, ensuring it is relevant, usable and up-to-date.
- Foster a culture of open communication in order to: 1. enable patients to seek support 2. enable staff to know how to provide support, and what to do if they are unsure or need additional advice in addressing an issue, and 3. allow for learning and reflection within the team.
- Seek feedback from patients about what support they would want to be available within your service provision.
- Source or develop training for the team relating to issues that are pertinent to your organisation.



'I could see the other relationships going on... just like everybody you want to be loved and that would make me a bit low...there weren't many girls...who were interested in a young man with disabilities.'
 MD, age 22 talking about his time at college

'Adult' activities



In order to achieve clarity and aid decision-making, the following principles have been developed by Helen & Douglas House, to be applied when there are requests for potentially contentious activities from any young adult:

- **Is the activity legal?**
Would agreeing to this request break any civil or criminal laws?
- **Where would the activity take place?**
There may be more restrictions for activities 'in-house' than for trips out.
- **Who would be responsible for arranging the activity?**
No member of staff should be obliged to participate in any action that offends their personal values or beliefs.
- **Who will pay for the activity?**
Charity money may not be used for funding activities that could be deemed to be inappropriate.
- **Could the activity cause offence?**
To other young adults or families, or members of staff.



So what went wrong at DH?



- Commissioned funding from health and social care was significantly less than anticipated
- Charitable giving for the care of disabled young adults is very limited – they are perceived as ‘independent’ and ‘less in need’ that dying children
- This may suggest that the ‘ideal’ in-patient age appropriate setting is currently not viable without changes in government policy.....

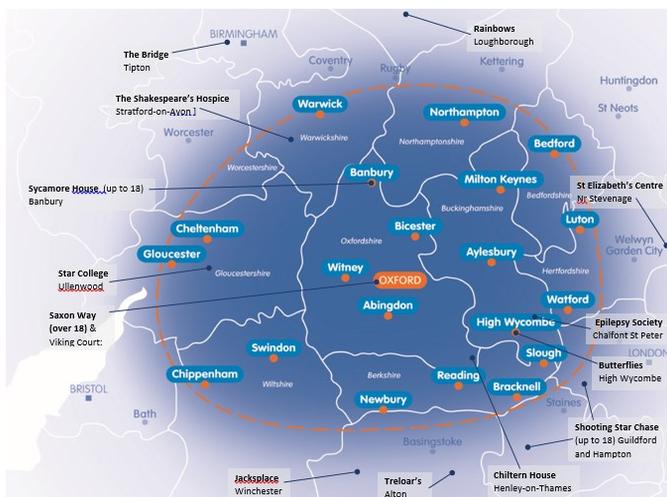


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Active Transition Support



- Dedicated full time Youth & Transition Worker post
- Associate Specialist Doctor post in Youth & Transition
- #Network Saturdays
- Dougie's Den (Teen Space)



- Communication
- Coordination
- Comprehensiveness
- Continuity
- Choice



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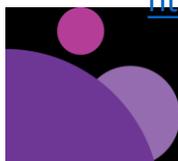
NICE Guidance (NG43)



Key Guidelines

- 1.2.6 Named key worker
- 1.3.4 Give young people and their parents information about what to expect early enough (School Year 9)
- 1.1.5 Services should work together
- 1.2.4 Hold an annual meeting to review transition planning

<https://www.nice.org.uk/guidance/ng43>



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NICE
National Institute for
Health and Care Excellence

NICE Quality Standards (QS 140)



- **QS 1:** Young people who will move from children's to adults' services start planning their transition with health and social care practitioners by school year 9 (aged 13 to 14 years), or immediately if they enter children's services after school year 9.
- **QS 2:** Young people who will move from children's to adults' services have an annual meeting to review transition planning.
- **QS 3:** Young people who are moving from children's to adults' services have a named worker to coordinate care and support before, during and after transfer.

<https://www.nice.org.uk/guidance/qs140>



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NICE
National Institute for
Health and Care Excellence

NICE QS 140



- **QS 4:** Young people who will move from children's to adults' services meet a practitioner from each adults' service they will move to before they transfer.
- **QS 5:** Young people who have moved from children's to adults' services but do not attend their first meeting or appointment are contacted by adults' services and given further opportunities to engage.

<https://www.nice.org.uk/guidance/qs140>



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NICE
National Institute for
Health and Care Excellence

Improving Transitions for Young People



- TfSLs funded ten projects to address the 'cliff edge' in care
- Aim to test different approaches to transition:
 - Volunteers matched to young people in last year of school - signposting
 - RCGP –Positive transitions in Primary care project - communication
 - Council for disabled children - expert parent program
 - Sexuality Alliance (Hospice UK) - video resources
 - Specific organisational projects
 - Sunderland Royal Hospital / Royal Devon & Exeter Hospital
 - Ty Hafan (transition hub)/ St Elizabeth's Hospice / St Oswald's (engaging GPs)



Final evaluation due Autumn 2021



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Voices of Young Patients



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TfSLs Focus Group for NICE

- 14 young people with LLC aged 12-18 (7 male, 7 female)
- Conditions included SMA, DMD, cancer, CF, as well as other rare degenerative diseases
- Interviewed in hospice or at home – focus groups and individual interviews (Bristol, York, London)
- All had capacity to consent
- Predefined themes were developed with the NICE Guideline development committee (including our lay members)

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Over-arching themes



- **Seeing us as an individual**
 - Most were keen to be involved in care planning – but preference varied
 - Providing timely, personalised information
- **Recognising individual needs and preferences**
 - Participants needs for information varied and changed over time
 - Involvement in planning conversations to the extend desired (only!)
- **Quality of care**
 - Continuity of relationships – particular concerns around transition
 - Feeling heard – not having to repeat oneself / have the same conversation twice
 - Desire to have access to a ‘specialist’ with specific knowledge of their condition
- **Emotional well being**
 - ‘Talking to others’ usually seen as helpful but some expressed and unmet need for this
- **Living as a young person**
 - Access to own technological devices with which to communicate
 - Own peers identified as a useful source of information



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Quotes – Seeking information



“I listen to other people with [my condition] ... I have a number of friends with [my condition], I’ve got three in [my area], so I talk to them quite a lot, because they’re all older than me so they have the experience.” (y3, age 14)

“It’s very useful having friends with the same condition because you can then swap notes...Me and [friend] are always like talking to each other about different experiences that we’ve had and, yeah, it’s very useful.” (y10, age 17)

“He [my dad] does make them find the answer. They can’t get away with not having the answer because they’re supposed to be the professionals ... I’m still learning to be an advocate for myself so I don’t really know what I’d do.” (y3, age 14)

“I think the doctor should do it first and bring it to you and see if you’re happy with it all.” (y14, age 12)



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Quotes - Controlling information



"If the doctor isn't giving you all the information, the doctor's not being honest. I think that they should give you all the information." (y3, age 14)

"I don't need information referring to my disability all the time ... I'm involved with the updates but halfway through I blank out and play games on the computer." (y3, age 14)

"I wouldn't always recommend it because sometimes it does give you like big over exaggerated information and that sometimes may cause panic." (y5, age 17)

(with reference to searching on-line)



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Last word to Lucy Watts...



We are part of a new, unforeseen generation. A generation that didn't exist even 15 years ago. The problem is, society hasn't quite caught up yet.

We are living into adulthood and we're wanting to go to university, to get a job, to have relationships, to live independently, and to have access to the same opportunities as our non-disabled peers.



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Questions?

