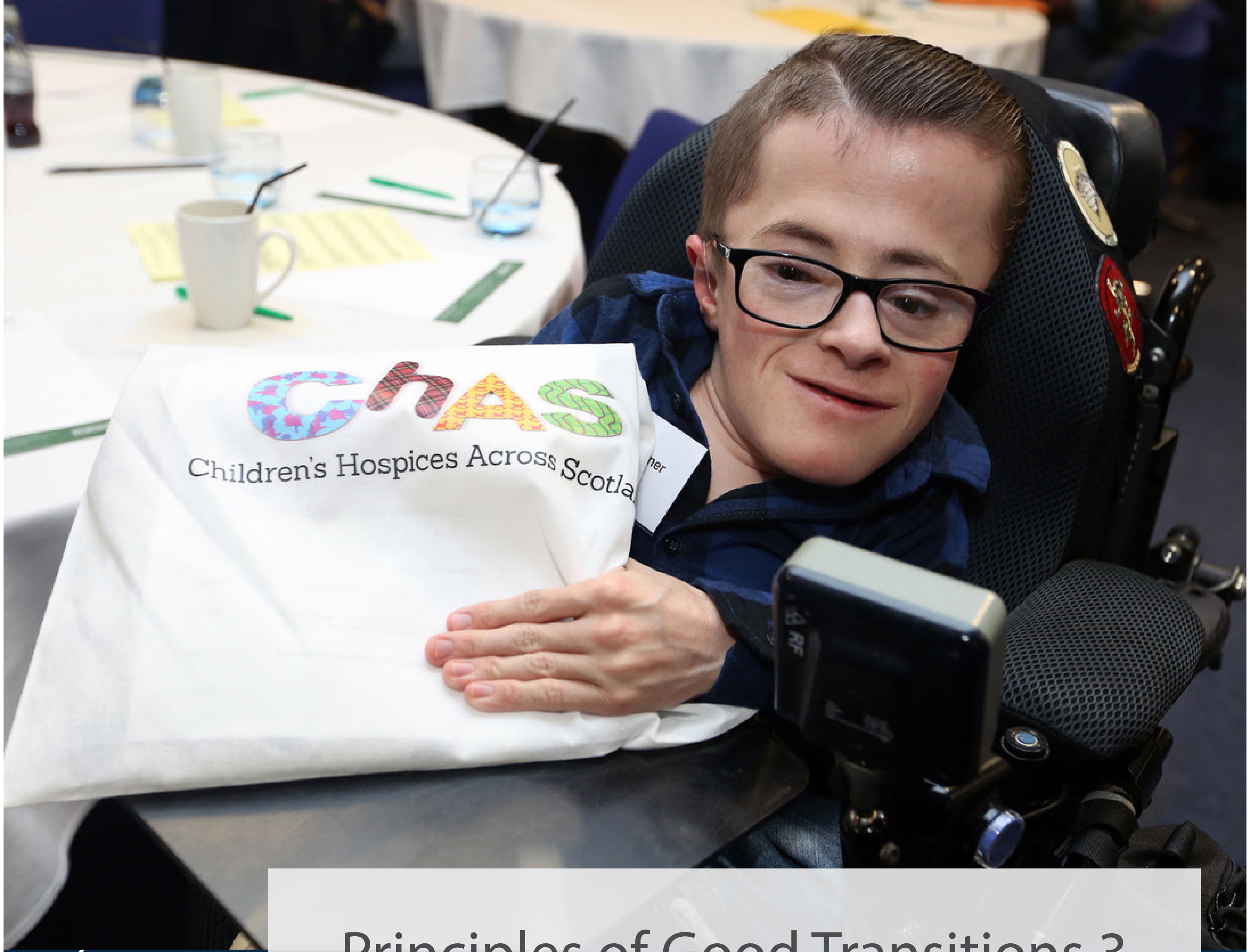

Principles of Good Transitions 3

Life Shortening Conditions Supplement, CHAS

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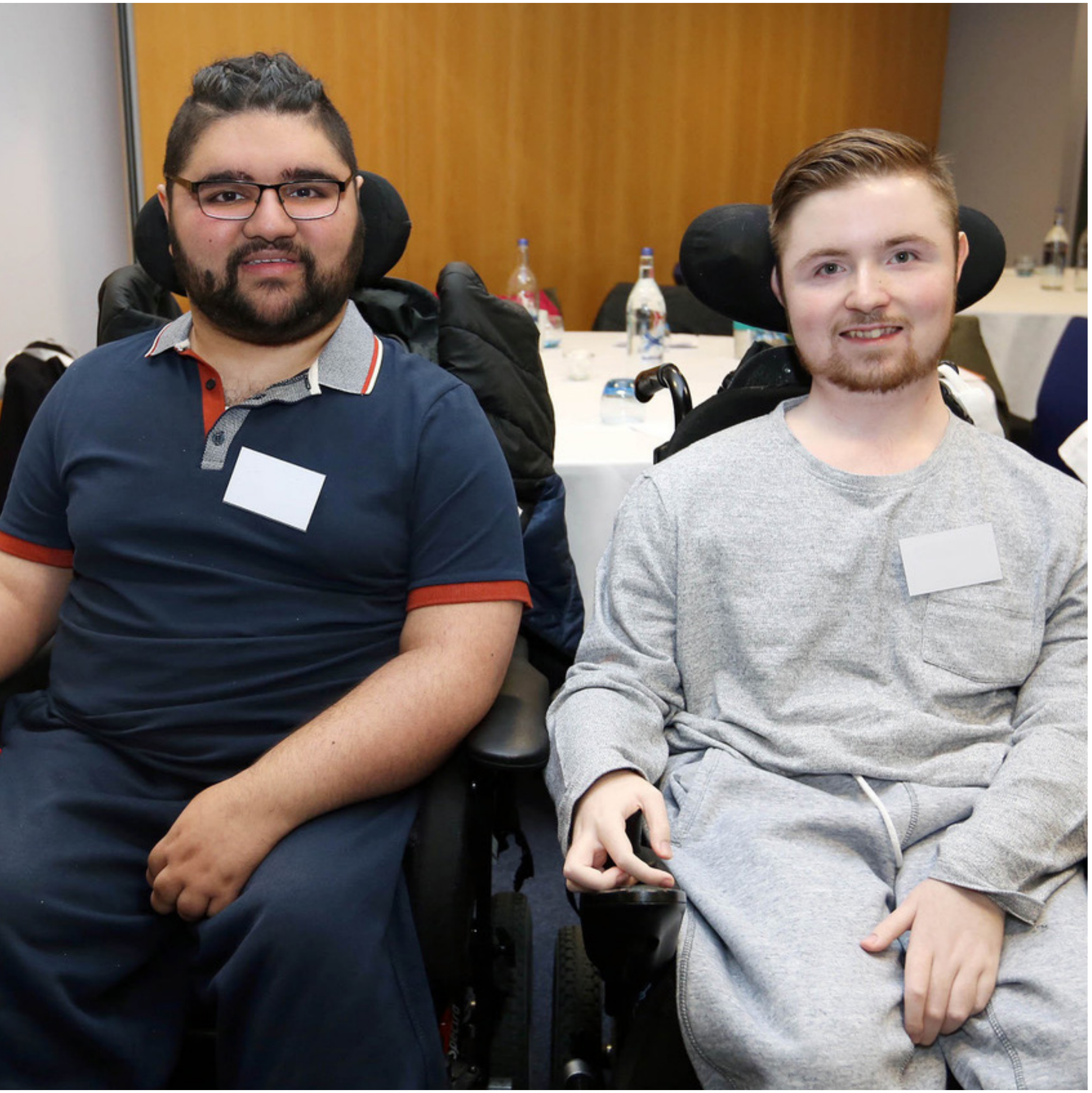
Introduction

This guidance is intended to be used alongside the newly launched Principles of Good Transitions 3 (2017). It is hoped this guidance will provide specific information for anyone who is supporting a young person with a life-shortening or life-threatening condition. Young people with life shortening conditions have complex health needs and will often require specialist palliative care, and it is important to have an understanding of these services as well as an understanding of the impact of living with such a diagnosis.



Background to CHAS and our transition work

The Scottish Transition Forum have an existing relationship with CHAS. They are both members of the Together for Short Lives 'regional action group' (RAG) and work in partnership to ensure transitions experience for young people with life shortening conditions is positive, and that their needs are highlighted.

Children's Hospices Across Scotland, better known as CHAS, is the national children's hospice service. We care for children with a life shortening condition and their family, wherever they are in Scotland. Three children die every week in Scotland from an incurable condition. Right now, CHAS can only reach one in three of these families. We are determined to reach them all, because we help families to celebrate the lives of their children whilst they are together and to honour their memory after they have died. We believe every family should have this opportunity.

CHAS cares for the whole family at our two purpose built children's hospices and also through our CHAS at Home team, who bring our services into families' homes, and our staff who work in hospitals and communities across Scotland. Wherever and whenever they need us, we are determined to be there for every family.

CHAS Transition Team was brought into being in 2014, following the introduction of our Transition Policy which created an upper age limit of 21years. Since then, the team has supported many young people over the age of 21 to move on to age appropriate services, helping young people with life shortening conditions to get the life they want and deserve.

What do we mean by life shortening, life threatening and life limiting conditions?

You will hear all three terms being used and it is important to distinguish between them, when considering how this may impact on a child or young person's schooling and transitional experience.

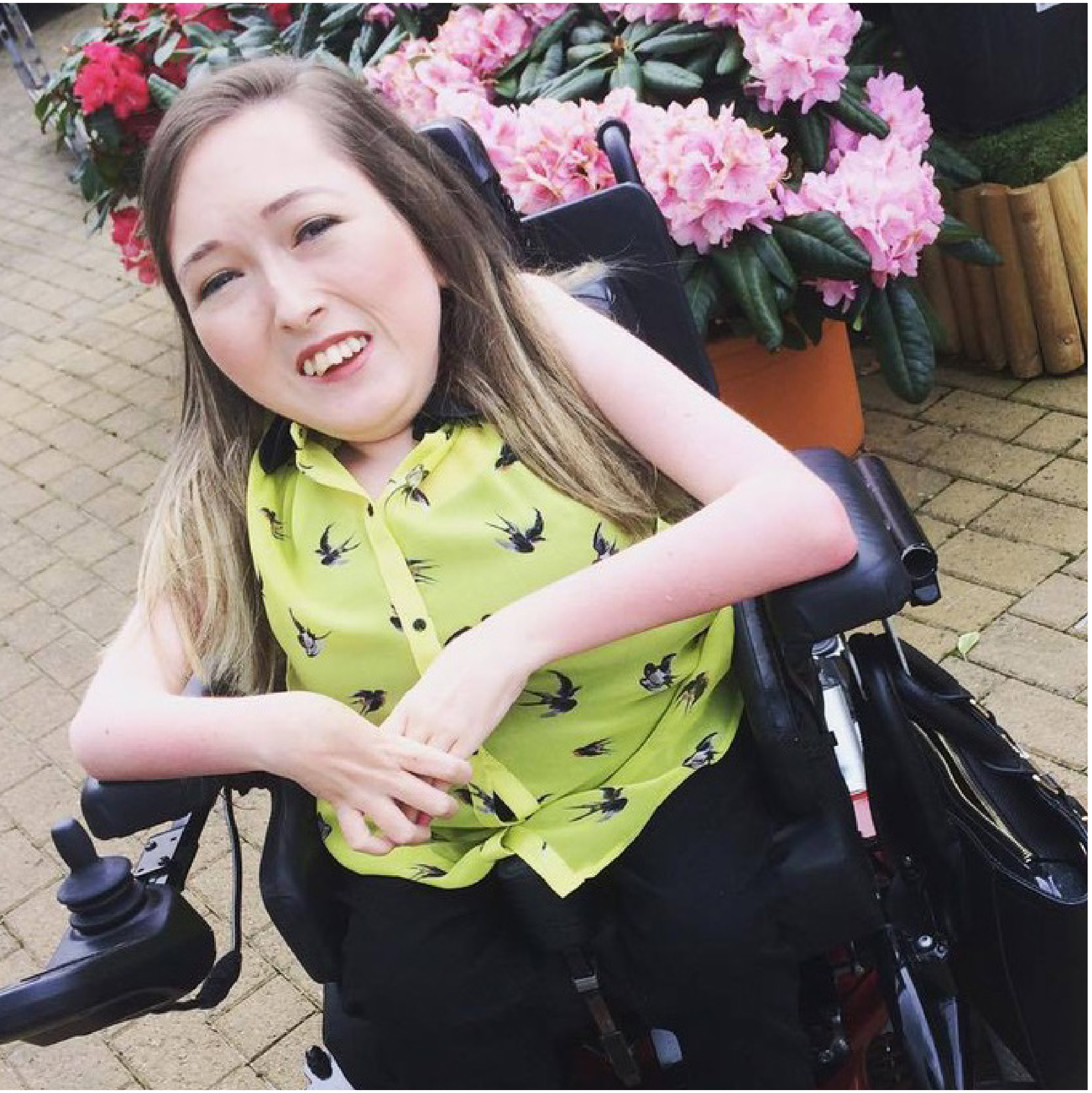
Life-limiting and life-shortening conditions are those for which there is no hope of a cure, and from which young people will die prematurely. Some of these conditions can cause progressive deterioration (such as Duchenne Muscular Dystrophy) which means the young person can become dependent on others for their care and support.

A life-threatening condition is that for which there is potential curative treatment but it could be unsuccessful (such as cancer). However, those young people in remission from cancer following successful curative treatment are not included.

What is palliative care?

Palliative care seeks to improve the quality of life of a person with a diagnosis that places them into one of the categories as described above. Palliative care for young people with life-limiting (or life shortening) conditions is an active and total approach to care, from the point of diagnosis, to death and beyond.

The approach embraces physical, emotional, social and spiritual needs, and focuses on the enhancement of quality of life for the young person, and support for their family. It can also include symptom management and the provision of short breaks, as well as end of life care and ongoing bereavement support.



Summary reminder of the Principles

1. Planning and decision making should be carried out in a person-centred way
2. Support should be co-ordinated across all services
3. Planning should start early and continue until age 25
4. All young people should get the support they need
5. Young people, parents and carers must have access to the information they need
6. Families and carers need support
7. A continued focus on transitions across Scotland.

Principle 1

Planning and decision making should be carried out in a person-centred way

- Young people with complex health needs often lose their voice and can struggle to communicate, sometimes because of a physical limitation such as a tracheostomy
- It is essential each young person is involved and consulted, and their voice is heard, when any decisions are being made
- To do this, their individual communication needs must be taken into account and any assistive or augmentative technology should be used to ensure they can communicate their wishes and desires
- Consider the use of an advocate if someone struggles to communicate or make their voice heard
- Those involved in supporting young people with LSCs must know how they communicate and what is the most beneficial way of engaging with them
- As with other young people with additional needs, if appropriate, staff should use communication passports; and consider how unique information is shared with those who will be supporting the young person after school
- Give consideration to their health needs, and the impact this may have on planning and decision-making; for example, consider the timing of meetings as it may be more appropriate to meet with a young person at a time when they are not receiving treatment and are at their most alert.
- Arrangements for planning meetings must be flexible to accommodate fluctuations in the young person’s health, which can change suddenly.
- The venue of any planning meeting must be flexible too - a young person with a LSC may spend considerable periods of time in hospital or at home
- This means that additional time must be given and preparation is crucial – you can’t leave planning and decision-making until the last minute and it can take longer to engage and support someone with a LSC to transition effectively and positively

As we are reminded by authors of a recent study commissioned by the Alliance, “Transitional support and planning is more likely to be successful if it is attuned to the developmental stage of the young person, taking into account the young person’s maturity, cognitive abilities, mental health, needs in respect of long-term conditions, social and personal circumstances and communication needs.”
Experiences of Transitions To Adult Years and Services, p.53

Principle 2

Support should be co-ordinated across all services

- Families, carers and friends who are important to the person should be involved in planning and supporting young people to move on
- Young people with complex health needs may have many professionals involved in their care and treatment
- It is important that all those people who know the young person well are involved in planning and enabling the transition – these people can provide specific condition-related advice and support which will help shape the person’s future
- If a child has complex disabilities and this could include learning disability or autism, then those services must also be represented
- It is essential that someone from Adult Social Work Services is involved (such as a social worker) and this person should understand what it means to be a young person with a life shortening condition moving into adulthood
- Having a transition coordinator involved can really help when someone has complex needs, to ensure a coordinated and conjoined approach
- Key players who are supporting the young person should have an awareness of their local areas and of all the opportunities that may be available to them
- Communication across agencies is essential to producing a coordinated plan

Example of Good & Effective Practice

Rory had a life threatening condition for which there was no cure and was being supported by CHAS and his primary care team. There was no involvement of social work or education when his condition began to deteriorate rapidly. His transition worker from CHAS referred Rory to his local palliative care team as well as to adult social work services, and spoke with those locally who needed to be involved to support his transition from paediatric into adult health care services. Support for Rory and his family was coordinated across all health and social care agencies, as well as including local third sector and voluntary organisations (carer centre support for mum, advocacy for Rory), and communication was open and positive between everyone. The transition worker assumed a ‘lead professional’ role, and was a central point of contact, which mum found supportive. There was a shared sense of purpose between all services and a coordinated, planned approach enabled everyone to provide the best possible care for Rory and his family and friends, in the end stages of his condition. Having the CHAS worker identified as ‘coordinator’ helped ensure good communication and gave a key point of contact during the transition to adult services.

Principle 3

Planning should start early and continue up to age 25

- Young people with LSCs can have fragile health and spend considerable periods of time off school with illness, or in hospital (or hospice care) receiving treatment. This impacts on planning and can slow things down
- Therefore, early involvement of relevant professionals and agencies is vital and people should be aware that these young people may need longer term support, and be committed to this
- The earlier the planning begins, the better!
- Schools and other agencies supporting the young person should start conversations around moving on as early as they can, and have a duty to begin to prepare the young person for adulthood through their approach
- Services such as short breaks providers should begin to prepare young people for adulthood at an early age, where appropriate, and enable skills to be developed; for example, involving young people in planning their breaks and enabling them to do household tasks such as menu planning, budgeting and food shopping
- All services involved need to understand the unique needs of a young person with a life shortening condition and how this impacts on their development; people and services need to be empathetic to these needs
- Services may need time to adapt their provision and to ensure staff receive specific training which enables them to meet the needs of the young person effectively (for example, specific training on the use of ventilation equipment)
- Adult Social Work services must be involved early to ensure that the person has time to complete a needs-led, person-centred assessment which will assess if they meet the eligibility criteria for an individual Self-directed Support budget for post-transition care and support
- Remember, the young person and their family may also be planning for changes in their condition, and perhaps completing an anticipatory care plan (ACP) which allows them to note their wishes should their condition change or they require end of life support. It is important to be sensitive and to feel able to have ‘difficult’ and courageous conversations with young people facing an early death.

Principle 4

All young people should get the support they need

- Young people with life shortening conditions may face daily limitations because of their disability, but should be offered as many options and choices as their non-disabled peers
- Young people with LSCs have to live with the impact of their illness and the losses this can expose them to. Transition is often another period of potential loss and uncertainty for them, and they may need specific services to help them cope, such as those offered by CHAS and adult hospice services
- Aspirational thinking can be difficult for this group of young people who have to face their own mortality as well as live with the daily consequences of their condition. Young people with LSCs face an uncertain future which can have a serious impact on mental health as well as their ability to aspire, to dream
- •Many young people with LSCs will have lost their peers and friends to the same illness, or even family members. Given that few of their non-disabled peers will have experienced the loss of close friends or family at such an early ages, the impact of this has to be recognised by services involved in supporting them during transition
- The impact of loss on the emotional and mental wellbeing of young people with life threatening illnesses should be taken into account, and any transition 'future' planning should be handled sensitively
- Consider linking young people with peers who can act as a buddy, and using networks that already exist which may be condition-specific (such as DMD Pathfinders)
- Direct young people to existing online resources and peer support services which can help support young disabled to access communities and get the life they want to live, (such as 'Euan's Guide' or 'DMD Pathfinders')

Allan, Eric and Blair are all teenagers with Duchenne Muscular Dystrophy who are working with transition staff from CHAS. All young men had questions about their illness and wanted to speak to someone about their fears and worries. All these young people had lost friends (and relatives) to the same condition, and as part of growing up they begun to ask questions about their own future and their prognosis, and to explore their own mortality. They didn't want to talk to parents, but wanted to know what lay ahead, and to find out how other peers have coped. Their transition worker in CHAS arranged a facilitated conversation for them with the hospice doctor and lead nurse, which allowed the young men to ask questions in an informal environment, with their peers around for support. The men asked questions they couldn't ask family or friends, and were then equipped to make choices about their future care and treatment, and felt a sense of being in control. It also reinforced supportive peer-group relationships.

Principle 5

Young people, parents and carers must have access to the information they need

- For young people with complex needs, information should be made available in an accessible format which works for them, and supports understanding
- Information may need to be presented in alternative formats such as symbolised options, talking mats, or on DVD
- The use of social media and online platforms to share information and carry out transition planning can also be helpful
- The use of technology can help engage a young person in the process
- Young people with LSCs may spend large periods of time isolated and without peers around them, either at home or in hospital. They can be supported to access information and to engage using appropriate adaptive technology, (such the use of eyegaze hardware for those with limited body movements)
- Consider the use of language – all information should be given in a language and format that the person understands, or can be supported to understand
- Remember to check the young person has understood what is being asked of them, or what information is being presented to them. Young people with LSCs may or may not have communication problems, and often struggle to make their views known or to understand what is being offered. However, their ability to verbalise may be hampered by their physical disability, and their communication can be compromised by the effects of some medication, or the use of specific invasive equipment
- The transition of someone with a life shortening condition may need to be paused or delayed if they become unwell - information should be given to them in a timely and sensitive manner, appropriate to their circumstances
- People involved should have information about specific services which are available for disabled people in their communities, and specialised services which can meet the needs of people with physical disability and complex health needs (such as condition-specific peer support groups)
- It is important to involve palliative care services as they can offer specific support to young people and also to their families and friends

Transitioning from children's services can often mean that young people, parents and carers have to get to know lots of new people and services at an already challenging time. The lack of appropriate information can leave people feeling unsupported and anxious, and parents report that it can be difficult to navigate the different services and know what is most suitable for their young adult. Transition workers within Rachel House hospice support this by signposting and introduction to new services, as well as provide access to information they need to make informed choices, as part of each person's individual transition plan. They have time to go with young people in transition to new places, to help them to navigate options for their future, and this time is vital when other statutory services can be limited.

For one young man with a form of muscular dystrophy, the introduction of eye gaze hardware technology allowed him to become independent online. HI transition worker secured grant funding to purchase the equipment for use at home, and he is now free to access the internet and social media platforms, which in turn allows him access to information about services he could engage with, giving him choice and control. It also meant he could access emails again independently and professionals he was referred to could communicate directly with him.

Principle 6

Families and carers need support

- Transition is an emotional and stressful time for parents of young people with life shortening conditions, many of whom didn’t expect their child to live into adulthood, and many report a feeling similar to ‘falling off a cliff’
- Some families of young people with life shortening conditions find it difficult to allow their child to move into adulthood, to consider them as adults, and will need support during this transition - for these parents, planning can be even more difficult and require time and a considered approach
- Advocacy and individual support should be offered
- Consider referrals to Carers Centres as means of support for families
- Adult palliative care services have a role to play and parents should be given information about these services and introduced to the concept of adult hospice care if appropriate
- There may be more than one affected child in the family, and support may be required for the siblings too

Working with parents around their own transition plan can help ensure that they feel listened to and that their needs as carers and parents are identified. Mary and John are parents and full time carers, who they felt anxious about the upcoming transition into adult services and stated they were unclear what supports would be available to them during this process. During introductory home visits, a dedicated transition worker explained the process and gave them as much information as was appropriate, as well as telling them what to expect and what has worked for other parents in this situation. Not only was information provided, solutions were actively sought and discussed. Mary said she felt reassured by this.

The worker also supported Mary and John to access their local carers centre, who will offer the child and young person support into adulthood and beyond. The family now have access to 1:1 support if needed, as well as access to information and group sessions which the whole family can benefit from. This approach throughout the transition has meant a well-supported transition process for this family who reported that they felt more able to deal with the process of transition for their child, as they felt comfortable that their own needs were also being met.

Principle 7

A continued focus on transitions across Scotland

There is a continued focus and commitment on transition within current Scottish Government policy and legislation. The Principles of Good Transition should be followed when supporting young people with life shortening conditions in transition.

As the recent ChiSP study indicated, there are growing numbers of young people with life shortening conditions living into adulthood (Fraser et al, 2015). The demands on services will therefore increase and we know there are more young people than ever before who will be transitioning into adulthood, and need specialist support to move on effectively. The report recommends specialist emotional and psychological support is available for everyone involved, and we must continue to develop skills in transitioning young people with complex health needs, to ensure a positive experience.

There is a need to develop services for young people with life shortening conditions, as well as to develop existing services and communities to make them ' fit for purpose'. Young people in transition need to have the same range of options for their future, and be supported to aspire to a life of education, work, relationships and friendships, and social and leisure opportunities. Agencies can learn from one another, from examples of good practice, and embed these into long term plans.

CHAS is committed to continuing to support the development of young people approaching, or in, this transitional phase in their lives. CHAS has employed specific transition workers in each of their hospices and there is a transition policy in place to support this work. Staff will continue to work closely with allied professionals in education, health and social care, as well as partners in adult palliative care services. Transition impacts on family and friends, whow must be given support to access appropriate information and services, and be linked in with adult hospice services if wished. CHAS works closely with partners at 'Together for Short Lives' who have a specific transition team focus

Resources and Information

ALISS – Scottish Government funded database of information about local services and resources that support health and wellbeing **https://beta.aliss.org/**

The ALLIANCE – partnership for health and social care providers and agencies, sharing resources and information **http://www.alliance-scotland.org.uk/**

Children's Hospices Across Scotland (CHAS) – Scotland's only provider of hospice care for babies, children and young people, and their families, including transition-specific workers **https://www.chas.org.uk/**

Disability Sports – online guide to organised sport and recreational opportunities for people with disabilities **http://www.disabilitysport.org.uk/**

DMD Pathfinders – user-led organisation for people living with Duchenne Muscular Dystrophy, offers information and peer support **https://www.dmdpathfinders.org.uk/**

Euan's Guide – reviews of facilities by disabled people for disabled people **https://www.euansguide.com/**

In Control Scotland – organisation aimed at helping people make best use of Self Directed Support and to be in control of their lives **http://in-controlscotland.org/**

NICE - the national institute for health and care excellence provides guidance and standards for young people moving from children's to adult services **https://www.nice.org.uk/guidance/qs140**

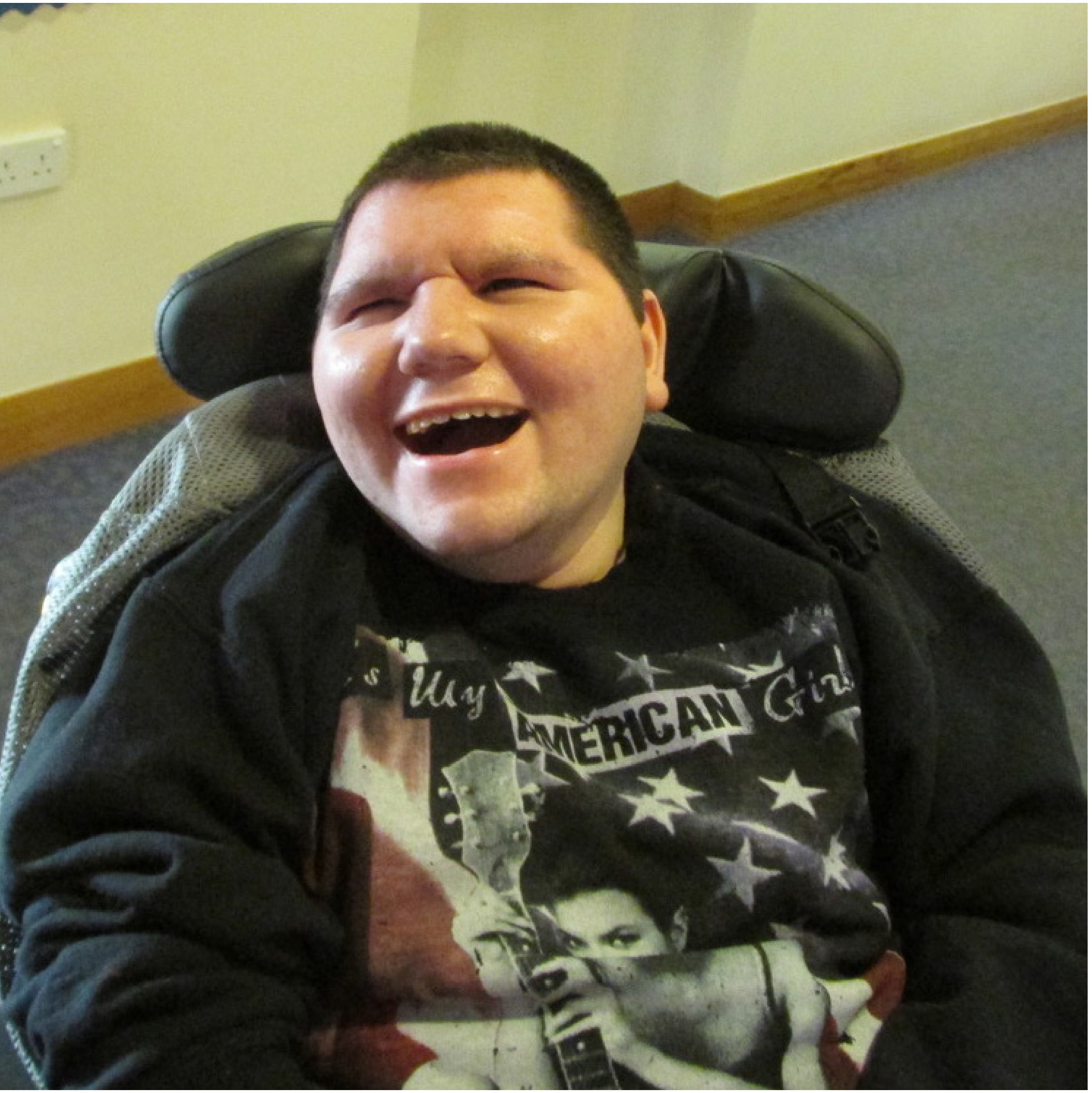
PCPLD network (Palliative Care for People with Learning Disabilities) – aims to increase awareness of the palliative care needs of people with learning disability **http://www.pcpld.org/**

Scottish Muscle Network – clinical network for children and young people with neuromuscular disorders **http://www.smn.scot.nhs.uk/**

Scottish Partnership for Palliative Care (SPPC) – brings together people to improve experiences of those experiencing deteriorating health, palliative care, dying and bereavement **https://www.palliativecarescotland.org.uk/**

The Scottish Transition Forum – aim to improve the experience of young people with additional support needs and provides information and governance, including the Principles of Good Transition 3 documentation **https://scottishtransitions.org.uk/**

Together for Short Lives – UK wide charity who support children and young people expected to have short lives **http://www.togetherforshortlives.org.uk/**



Research

Facing the Future Together ARC Scotland 2017, Scottish Transitions Forum/ARC
http://scottishtransitions.org.uk/blank/wp-content/uploads/2017/07/Facing-the-Future-Together-Report.pdf

Experience of Transitions to Adult Years and Adult Services 2017 Scottish Government, and The Alliance
http://www.alliance-scotland.org.uk/news-and-events/news/2017/05/experiences-of-transitions-to-adult-years-and-adult-services-new-report/#.WcynksJwbcs

The ChiSP Study– Children in Scotland requiring Palliative Care:identifying numbers and needs Lorna Fraser et al University of York (Social Policy Research unit) (2015)

Moving to Adult Services – what to expect 2017
Together for Short Lives

ARC Scotland

gov.scot