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My Life

Growing up and
living with Ataxia-
Telangiectasia: young
people's and young
adults' experiences

Bryony Beresford,
Nicola Moran and
Susan Clarke

My Life: Growing up and living with Ataxia-Telangiectasia: young people's and young adults' experiences

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2013

A report of the My Life project:
A study commissioned and funded by the A-T Society



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The team would also like to thank the A-T Society for their support. Particularly their work in telling families about the project and inviting them to participate, and for providing an opportunity for us to present preliminary findings of the project at the family weekend in earlier in the year.

1: About the My Life project

In spring 2012, the A-T Society commissioned the Social Policy Research Unit (SPRU) to conduct a piece of research about young people and young adults¹ with Ataxia-Telangiectasia (A-T). The A-T Society was seeking to understand more about the lives of young people, their priorities and aspirations, and what got in the way of them living the lives they wanted to live. The Society also wanted to know young people's views about the support and services it provided to young people with A-T and their families.

The research

Eleven young people (aged 16 – 27 years) and ten parents of young people (aged 16-27 years) responded to the invitation to take part in the My Life project. The parents and young people were not all related. Thus a total of 12 families were represented in the project: four young men and eight young women. This represents around a third of all young people in this age group with the condition in the UK.

The young people were visited by a member of the research team for their interview. Parents were interviewed over the telephone. Interviews took place between May and June 2012.

The main part of the interviews with young people focussed on discussing areas of their life which were important to them and with which they were happy and content; the interview then moved onto aspects of their life they would like to improve or develop. Finally, the interviews explored the things which the young people perceived as gaps in their lives. Throughout, the interviews explored what supported and hindered the young people achieving their desires and aspirations. The final part of the interview explored young people's views about the A-T Society and their views and opinions about how the A-T Society could be improved or developed so that it better meets the needs of young people with A-T. The interviews with parents followed a similar structure.

The report

The key purpose of the My Life project was to hear, and give a voice to, the experiences of young people with A-T. Whilst we also interviewed parents, we prioritise the young people's views and experiences and, almost exclusively, use quotations, or excerpts, from the interviews with young people to illustrate a point. We do, however, report diversity of

¹ For ease of reading we use the term young person from this point forward. It refers to young people and young adults aged 16 – 27 years.

views and opinions between the young people and parents. In addition, the data from the parents' interviews has been used to supplement, or add further detail, to what we learnt from the interviews with young people.

2: How the young people viewed their lives

Levels of satisfaction or contentment with their current lives varied considerably across the sample of young people we interviewed. The sources of dissatisfaction or unhappiness were because the young people perceived their lives were lacking in some way and/or the deteriorations in their physical functioning and health.

The young people identified a number of facets to a good quality of life:

- meaningful and stimulating day-time occupation(s):
 - studying or vocational training
 - volunteering
 - paid work
 - interests and activities
- friendships, and spending time with those friends;
- positive emotional health;
- independent mobility inside and outside of the home;
- opportunities for independence and, where desired, living independently;
- money;
- health care.

Not unexpectedly, the things which young people identified as positive features of their lives were, for others, identified as a gap in their lives which they wanted to remedy. A range of people and resources supported, or enabled, a good quality of life, including parents and carers, mobility equipment, computers, community/mainstream and specialist services.

In the following sections we report each of these 'life areas' in greater depth, including the specific ways in which the young people believed the A-T society could enable them to live their lives in the ways they wanted to live them. In the final section we report the young people's views of the A-T Society and further suggestions for the ways in which it could develop its support for young people with A-T.

A note about parents

The majority of our interviewees were still living at home. In the interviews we did not particularly focus on family life and specific data on this aspect of young people's lives is, therefore, inevitably very limited. However, across the different topics we discussed with young people, parents' care and their roles in supporting them in their day to day lives was clearly evident in the young people's accounts. The young people also valued and took pleasure from the company of their parents and siblings and the activities and experiences

they shared together. These made significant contributions to feeling good about life. As with any family, trips and holidays were high points which were often spontaneously recalled by the young people.

Overall, parents' views about their son or daughter's lives, and what they felt were the priorities for change in terms of improving or enriching his or her life, were in accordance with those of the young people. Any differences were differences of emphasis or priority, rather than contrasting or conflicting views.

Finally, the interviews with parents were very focussed on the young people and their lives. Parents did not use the opportunity of speaking to a researcher to bring into the conversation their own needs and experiences as parent/carers. This is very typical of parents of disabled children and young people: they find it hard to dwell on or pay attention to their own needs, prioritising instead the needs of their son or daughter. An absence of reference to parents should not be taken to imply that issues, concerns and unmet needs do not exist for parents/carers of young people with A-T.

3: Meaningful and stimulating daytime occupations

Three of our interviewees were in full-time education, either attending a local special school or a residential special college. The extent to which the remainder of our sample had routine or regular activities during weekdays is set out in Table 1.

Table 1: Number of days in the week when young person has routine activities or commitments for at least part of the day

| ID. | Activity in mainstream setting (e.g. shopping with carer, exercise class) | Activity in specialist setting (e.g. day centre; disabled sports/ gym facility) | Voluntary or paid work | Education/ training | No. of weekdays with routine activity |
|---|---|---|------------------------|---------------------|---------------------------------------|
| A | - | 1 | - | 1 | 2 |
| B | 1 | 0 | 2 | 0 | 3 |
| C | 0 | 0 | 0 | 3 | 3 |
| D | 0 | 5 | 0 | 0 | 5 |
| E | 0 | 0 | 0 | 0 | 0 |
| F | 0 | 3 | 0 | 1 | 4 |
| G | 0 | 2 | 1 | 0 | 3 |
| H | 3 | 0 | 1 | 0 | 4 |
| <i>Number of young people participating in activity</i> | | | | | |
| Total | 2/8 | 4/8 | 3/8 | 3/8 | 7/8 |

Table 1 shows the range of level of involvement in routine activities or commitments during weekdays for the young people we interviewed who had left full-time education. Three of the young people we interviewed had routine activities or commitments for four or five weekdays, and a further three had something on three days of the week. One young person had routine activities on two weekdays and, finally, we interviewed a young person who had no routine activities or commitments during the week. It is important to note that almost all the activities recorded in this table did not occupy the whole day.

Having meaningful and enjoyable things do on a routine basis was very important to the young people. They wanted to feel occupied and to have a sense of purpose.

...that's why I keep so busy, because if I didn't I would go out of my brains².

²In order to preserve anonymity, details of the characteristics of the speaker are not provided. In addition, on occasion minor details within a quote have been changed to protect identities.

Tiredness and interspersing the week with times of rest was a factor which was commonly identified as limiting the young people's participation in activities, work, education or training. However, the great majority of those interviewed desired to expand and develop their weekday occupations and activities.

I try to fight against any demand that I've got to go to bed.

In terms of social and leisure activities, many young people reported a significant lack of services and clubs which were right for them, both in terms of the other people who go along and/or the activities on offer.

There's nowhere to go....there's nothing to do round here.

Another thing I would love to do is wrestle. I would like to give it a try....I would like some other things to try out and have a go.

The [A-T Society] trips to Dublin and Falmouth were amazing, but the Vitalise holidays are just not my cup of tea.

This was particularly the case when their physical limitations meant accessing mainstream settings was difficult, if not impossible.

I would go swimming but the disabled changing room is too small.

Equally, some described activities they aspired to participate in but perceived them unrealistic given their physical limitations.

There are things I'd like to do but they're not really suitable for disabled people.

It is interesting to note here that key themes in the young men's descriptions of the sorts of activities in which they would like to take part included: risk, adventure and physical challenge. Within the context of day or respite services, what may be regarded as risky or challenging for people with learning disabilities or older people may not be the case for young adults with physical impairments and, particularly perhaps, those who had previously been non-disabled.

I mean like quad biking, racing, off-roading and things....I'm always up for a challenge!

Work

All those who worked described it as a very enjoyable and important part of their lives. Some found it had extended their social lives through friendships made with work colleagues.

Work was an area of their lives that the young people consistently saw as a priority for change. Almost all those we interviewed had aspirations regarding work, either:

- to obtain work, in a voluntary or paid capacity;
- to extend the amount they worked;
- to move from voluntary to paid work.

I'm independent and want to increase my independence. I hate being on benefits....it's really, really confidence-knocking.

Interestingly, the importance to the young people of paid or unpaid work did not emerge as such a strong and consistent theme in the interview with parents.

As with other day-time occupations and activities, tiredness was identified as influencing the feasibility of securing and sustaining paid work. A lack of opportunities and transport/access issues (for example, charity shops suitable work setting because of poor wheelchair access) were cited as hindering young people's chances of gaining both paid or unpaid work.

Further barriers with respect to paid work which the young people perceived or had experienced included:

- a lack of work experience;
- a lack of skills /qualifications;
- financial costs of undergoing further education/training;
- a lack of information and guidance with respect to seeking and obtaining work;
- the cap on earnings imposed by rules associated with entitlements to benefits;
- hospital appointments and/or demands of treatment regime;
- job centre staff lack of understanding and expertise;
- a lack of understanding fuelling discrimination on the part of employers.

I need someone who totally understands about the condition and can help get across to employers about A-T and that it's not as bad as they probably think.

At the end of the day, I've got a degree so I've tried to better myself and no one gives me a chance.

Getting work is so much harder because I have a disability. I do honestly believe that people still discriminate even though it's illegal.

At the Job Centre I have been in touch with a Job Centre Adviser who is for disabled people but I don't think she was that good, to be honest..... it was kind of like she told me what I already know.

Above all these barriers, the current economic climate was seen to further decrease the chances of securing paid work.

Finally, it was clear from our analysis of the interviews that low confidence and/or self-expectation were also affecting the young people's aspirations regarding work.

I can't do much anyway.

Adult day and respite services

Experiences of adult services were very mixed. Some young people spoke very positively about some of the activities and settings where they spent time. A small minority were using a lot of day services and these ensured their weekdays were busy and varied. Most who used day services spoke of very positive relationships with staff in these settings. It is worth noting here that the loss of similar relationships with staff based in children's services was, for some, one of the key areas of difficulty associated with transition.

Others found that specialist day services tended to be geared towards much older people and/or those with learning disabilities. The activities offered in these settings did not align to the young people's interests or preferences, and they had nothing in common with the others attending. This experience typically resulted in the young person stopping using a service, or reducing their use of it.

A minority were still using children's/young people's hospices though some reported loss of access to this service since turning 18 years. None reported using adult hospices. Hospices were always spoken of in a positive manner which was attributed to the breadth of activities available, the opportunity to meet with other young people and being able to choose what to do.

...basically you get to do what you want, really. Like you don't have to do certain things, you can do anything you like.

Support from PAs and carers

Almost all the young people we interviewed had one or more carers (or personal assistants (PAs)). Among those not using carers, only one young person would have liked to have had access to carers. In this instance, this support had been lost on the move from children's to adult services.

In various ways carers enabled greater independence; the young people could choose how to spend their time (rather than be constrained by activity programmes more typical of day centre provision), and it enabled them to participate in activities without drawing on the support of parents or friends. This served to enrich the young people's lives. Thus carers were being used to support the young people in the following activities: shopping, going to the pub, clubbing, cinema, theatre, gym, time at home spent playing (video) games, baking, accompanying on holidays and supporting the young person when at college or working.

My carers are a pretty good area of my life.

Carers were also used simply as company when nothing specific was planned. A minority (both those living in the family home and those living independently) also used carers for some elements of self-care. Young people were using direct payment and disability and employment support allowances/benefits to pay for this support.

So I find that's what works best for me....like I'm doing now: just employing people to help me and stuff, like when we go on holidays.

Overall, there was no strong sense of dissatisfaction with the amount of carer support the young people received. Almost all spoke of the need to have quiet times during the week for resting in order that they could be active and go out and about at other times.

As noted earlier, the primary gap in services for many was lack of appropriate social opportunities and/or leisure/pastime activities. However, there were instances where having a carer/personal assistant may have supported improved quality of life.

The quality of carers was reported to be variable, however. Young people and parents stressed the importance of the young person feeling they had a warm and positive relationship with their carers, that they were fun and good company, were reliable and, for some, could be trusted to carry out self-care tasks in the way the young person wanted them provided. Many young people expressed a strong preference that their carers should be around their own age. In addition, some young men noted it was good to have male carers as they would have shared interests in activities such as watching sport and gaming.

I think [younger carers] have got more energy. They've got a lot more get up and go!

It is important to note here that many parents were still heavily involved in caring. This included arranging and accompanying to activities, 'keeping an eye on', a source of companionship, and supporting self-care. This could be the case even when the young person had moved from the family home.

I have my own space and, like, I do things by myself. My mum's just next door so she comes to see if I'm alright and makes meals and that. I don't have carers 'cos my mum does everything for me.

Education and training

We have already reported that a lack of qualifications was viewed as a barrier to working. The social context of educational settings has also been referred to in other sections of the report, particularly young people's views on specialist vs. mainstream settings. The positive views of residential college, particularly in terms of providing opportunities to be independent is also covered elsewhere.

This section therefore focuses specifically on the education/training *per se*. Many of our interviewees had left school or college a while ago and were not engaged, nor aspired to, any further study or training. For some, however, studying was a source of enjoyment and satisfaction.

A minority had encountered barriers to studying. These included:

- institutions and/or examination boards failing to adapt a curriculum to accommodate the needs of students with physical disability;
- special school/colleges failing to offer courses to the level desired by the young person.

I've been told they haven't got the level that I want to do stuff.

Daytime occupation: how can the A-T Society help?

The young people identified a number of barriers to enriching and developing their lives and, particularly, what they did during weekdays.

The young people we interviewed identified a number of potential roles the A-T Society could assume to help them overcome these barriers and support this area of their lives. These included support to individuals and organisations as well as adopting a campaigning-type role, namely:

- Support to find paid or voluntary work;
- Information and advice to potential employers / workplace settings;
- Supporting young people and families to identify local services, activities and opportunities;
- Awareness raising/campaigning for improvements in services for young people with physical disabilities using adult social care.
- Awareness raising/campaigning at a local or national level regarding access to mainstream services and community facilities.

Being able to get out and about is inextricably linked to the opportunities available with regard to daytime occupations and activities. Thus the help towards the cost of motorised wheelchairs and/or driving lessons which the A-T Society provides makes a significant contribution to young people's outcomes in terms of being meaningfully occupied during the day (see also Section 6). The comments and suggestions reported in Section 4 (Friendships and social networks) are also relevant to ensuring young people have rich and fulfilling lives.

4: Friendships and social networks

Almost all the young people we interviewed expressed a desire for change in the area of their life concerned with friendships and social networks. It was a key priority, both for the young people and parents. A number of different aspirations were expressed:

- opportunities to take part in social activities with peer group;
- more opportunities to meet up with and spend time with existing friends;
- to have a boyfriend or girlfriend;
- friendships with others with A-T or similar conditions.

It is important to stress that friendship and social networks do not only fulfil emotional and support needs, they also mean that young people are doing things by going out to meet up with friends and engage in activities and shared interests. Equally, participating in activities can be way in which social networks and friendships can develop. For example, we came across examples of young people who had developed friendships with work colleagues.

The young people's different living situation did not appear to be associated with levels of social isolation. Thus there were instances of high levels of social isolation among those still in full-time education, young adults living in the family home, and those living independently.

The loss of previous friendships or social networks was a key factor underpinning the priority given to improving or developing social networks and friendships. Leaving school or college and/or the deterioration in their physical abilities and speech problems were identified as the key reasons for this.

Things with my old friends are 'complicated': sometimes they are my friends and sometimes not.

It's hard to meet up with my friends because they are working and things.

Leaving residential school or college meant the dispersal of friends, physical limitations (tiredness, mobility) and financial costs made staying in touch and meeting up very difficult.

I only keep in touch with a few friends I made there [residential college] because they're all down south.

Some reported that limited fine motor skills meant that they were unable to use social networking sites. Broken computers or laptops were also reported. Growing levels of

impairment meant some found friendships with non-disabled friends drifted or were difficult to sustain because of the increasing differences between their lives.

I do see friends sometimes: we go out for a drink or something.

A lack of opportunities to meet up with existing friends was also reported. None with special school or college saw friends from these environments at weekends or during the holidays. In addition, friendships developed through attendance at clubs or activities were not extended beyond that setting.

A number of young people described their personal assistants, or carers, as playing a key role in ensuring they had a social life. For example, some used their carers to enable to meet up and go out with their friends or alternatively to accompany them on nights out. Many acknowledged and were grateful for, the company and opportunities afforded through their carers. Some described their carers as 'friends', indeed one or two reported they were their only friends. There was a sense that some young people recognised the unusual nature of their relationship with their carers, endeavouring to reconcile the employer-employee dimension.

On Wednesday I see my PA. She's more like a friend because she takes me out. It's not really work for her because I'm so independent... so it's more like a day out for her.

It is important to note that the young people made a clear distinction between being among and spending time with other (young) people and feeling that they had friendships in those contexts. The former was experienced in settings where they felt different to others there. The source of this difference could be type of disability, age or the lack of disability. Almost all the young people who spent time (or had spent time) in 'special needs' settings, or used specialist services predominantly being used by young people or adults with learning disabilities or autistic spectrum conditions and/or much older physically disabled adults, described this as an issue.

I used to go to a social club for disabled people but stopped that because the people that were going weren't really my sort of people.

The other students are different. ... not to be rude or anything, but different mentally and stuff.

I used to go to a club but the people had learning disabilities and I don't have learning disabilities.

However, it is important to stress that this was not something that bothered everyone we interviewed.

Most of my school friends are in wheelchairs like me. They've got physical and mental disabilities. I am happy with my friends.

Sometimes the source of difference was the presence of disability *per se*. Thus some of those in mainstream education described them as isolating settings. This young person is contrasting their experiences in college compared to special school.

I call them my friends but they're not really. They're just people that I meet. We're not going to bump into each other when we're older are we? I had friends [at special school] because they're kind of like me.

Spending time in settings where peers were not identified as being potential friends resulted in some young people spending most of their time with the staff as opposed to other service users.

Boyfriends and girlfriends

A small number of interviewees had boyfriends or girlfriends: these relationships had developed from friendships in school or via on-line dating sites.

My boyfriend is one of the best parts of my life. He's very good with my A-T: he can't do enough to help me.

For one or two their boy/girlfriend was identified as the only friend they had. A significant minority reported wanting to have a boy/girlfriend, and that this was a high priority for their lives.

I'd like a boyfriend: it's just finding them! I'm working on it!

Meeting others with A-T

The opportunity to spend time and develop friendships with others with A-T, or "similar conditions", was a common theme in the interviews. The characteristics which emerged from young people's accounts as defining a condition as "similar" included: the absence of learning disabilities, the experience of deterioration, physical limitations and/or being a

wheelchair user. Friendships of this nature were perceived to offer something unique, namely the comfort and support gained from a shared experience.

I find it hard talking to people. But with other young people with A-T, you've got something in common with them and you can talk to them about what they find hard and what you find hard and you can compare.

To have someone who knows exactly what I'm going through would be superb.

It was clear that the rare nature of the condition contributed to the sense of isolation the young people experienced.

It would be great if there was people around me with A-T who lived nearer.

I feel so isolated 'cos no one else I know has got A-T, there's probably no one else in this county.

There's no-one who's, like, got what I've got so it's hard.

I can't get to talk to people with A-T. No-one's got A-T. No-one understands me. Just to talk to people who have the same problem as me would be good.

Some of those we interviewed said that, the main benefit of the A-T Society family weekends and young people's events and holidays was the opportunity they provided to get to know and spend time with others with A-T.

I only see them at the family weekends, but they are all my friends. I look forward to meeting them, I do.

A couple of young people also reported that their hospice arranged things so that their stays coincided with others with the same or similar conditions.

I know some of the people who go there....they've been there before...we talk to each other.

However, it should be noted that whilst these more occasional opportunities were valued, the young people were also very clear that they would like to develop friendships with young people in similar situations and with similar experiences that lived locally.

It would be nice to meet other people like me who live nearby.

Friends and social networks: how can the A-T Society help?

The A-T Society was consistently identified by the young people as having a key role in enabling young people with A-T to meet and develop friendships with other young people with A-T and/or similar conditions.

The young people wanted three different sort of support:

- opportunities to meet and spend time with other young people with similar conditions living locally to them;
- support with linking up and spending time with other young people with A-T;
- help with finding a boy/girlfriend.

Many said that the A-T Society had linked them up with others with A-T in the past and they had been in contact via social networking sites, texting, phone calls etc. However, a common report was that, over time, contact dwindled and was eventually lost. Regular provision of opportunities to get in touch with other young people was a solution put forward by the young people.

The newsletter was very popular with young people, especially articles about other young people. In this past this had led to young people making contact with each other. Interestingly, the Facebook page was not visited regularly by any of the young people and some were not aware of its existence. Awareness and use of the A-T Society website was much higher. However, it is important to note that a sizeable minority of those we interviewed did not have access to a computer/laptop, or did not/could not use one.

Weekend events and holidays were popular and, for some, were precious times of being with others who shared the same experience. The young people felt that a greater range of the type of activity weeks/holidays and weekend events would widen their appeal.

Ideas and suggestions to improve the support the A-T Society provided in this life area, or to develop their provision included:

- More articles in the newsletter about, and/or written by, young people.
- Work with local/regional respite care providers, such as hospices, to coordinate stays of young people with A-T/those with similar conditions.
- A dating / matching service for young people with A-T and similar conditions.
- Help to find others living nearby with similar conditions.
- Introduce a more young-person focussed approach/activities to the family weekend. For example, more 'high adrenaline' activities; more time for socialising, including activities which act as 'ice-breakers'.
- Have a stronger young person 'presence' on the website, with dedicated pages and opportunities for communication.

5: Emotional well-being

Drawing across the interviews a number of threats to emotional well-being were identified. Threats to well-being originated from symptoms, or manifestations, of the condition as well as the impact of those symptoms on everyday life.

The following aspects of A-T and living with A-T were seen by the young people as affecting their emotional-well-being:

- experiencing deteriorations in physical functioning;
- having a condition which is without cure;
- tiredness;
- loss of friendships and social isolation;
- being dependent on others;
- the lack of meaningful day-time occupation;
- discrimination.

If I'm tired I physically can't be bothered. I literally can't be bothered to do anything.

My old friends think that because I'm disabled now I won't want to do certain things. I find that quite upsetting.

We used the disabled toilet the other day and because I wasn't in a wheelchair we got evil stares because we looked 'normal'.

Sometimes people think, "Oh, she's disabled so she can't make decisions"...that really winds me up.

I feel happier. The fact that I am getting out more, and meeting people, my confidence has hit the roof, much more than what it used to.

Deterioration, identity and emotional well-being

Deterioration in physical health and functioning are core features of A-T and it was clear this had a strong influence on the young people's lived experiences. The loss of the ability to walk, (increasing) physical tiredness, and difficulties with speech and communicating were identified as impacting on, among other things, the inter-related concepts of identity and emotional well-being.

Losing the ability to walk and the shift to using a wheelchair on a permanent basis was described in very negative terms, such as “bad”, “depressing”, “hard” and “frustrating”. Parents described this loss as “demoralising” and causing a “loss of confidence.”

I wish I was still able to walk.

I thought of employing a load of scientists to like make a robotic suit that might make disabled people walk.....just like transformers.

The loss of motor abilities meant that the young people’s identities were threatened or compromised. Existing abilities and levels of independence were lost, and skills, sources of interest or enjoyment may no longer be feasible or possible aspects of their lives. The change from being an active and sporty child to becoming “wheelchair bound” is considerable.

*He used to be a very active child, so losing his mobility has been doubly hard.
(Parent)*

Deterioration meant that lives built around the ability to be independently mobile with similar energy levels to peers could not be sustained. The young people described the consequences of this in lost friendships and contact with peers, and a ‘narrowing’ of their life-worlds.

The earlier lived experience of being an able-bodied child or teenager meant that, for some, whilst not identifying themselves any longer as non-disabled, neither did they identify themselves as disabled. The gradual deterioration in physical functioning, tiredness and frail health is very different to most disabled young people’s experiences who, typically, are born and grow up with limited ability and specialist settings will be familiar, if not ‘normal’, contexts to them. In contrast, some of the young people with A-T described feeling out of place in these settings.

I kind of don’t belong.

I’m looking around thinking, “I don’t belong here really because I don’t need much help”.

Support with the emotional impacts of living with A-T

All the young people we interviewed believed that friendships with others with similar conditions, and particularly with A-T, and the opportunity to spend time together was a key

element of meeting their emotional support needs. This is illustrated in this quote from a young person who was anticipating meeting up with another young person with A-T:

I can't wait. It will be brilliant. They said they feel the same as me.

However, it is important to note that only a small minority were routinely in contact with others with A-T aside from special events or holidays.

Parents were commonly identified as a key source of emotional support: someone they could get upset with, be comforted by and talk to. None expressed as desire to seek professional help.

I have down days and up days. And when I'm feeling down my mum keeps telling me to speak to a psychiatrist.... but I'm not speaking to a stranger.

However, those using a counsellor or mental health service found it very helpful. None were using the counselling service provided by the A-T Society; most were unaware this was available.

I can say anything I like basically to him [counsellor].

Over and above this, some young people revealed the internal strategies they used to adapt and adjust to the impact of their condition on their lives. Some talked of comparing their situation to others in worse health. Others spoke of the need to accept what was happening to their bodies and focus on making the best of it.

Just looking at the kids and young adults in there [hospice]...that just upsets me and makes me stronger. I do like going for that reason.

My attitude now is that I have got A-T, there's nothing I can about it so just deal with it. That's what I do try to put in my head.

Parents' perspectives

Emotional and mental health issues were topics that we approached cautiously in the interviews with young people. 'Openings' were provided during the interview but we were led by the young people as to whether the conversation turned in that direction. We were, however, more directive in our interviews with parents on this topic. Most parents described their young person as being generally happy and content. However, they were also very clear that events or situations which reminded or reinforced the young person's

loss of abilities or brought to the fore the chronic and life-limiting nature of their condition threatened this emotional equilibrium. Examples parents gave included: being treated as having learning disabilities, loss of walking ability, not being able to keep up with able-bodied friends, being unable to wear particular fashionable items of clothing and, with age, realising the full implications of their diagnosis. Many parents felt that hormonal changes associated with adolescence contributed to emotional fragility. A minority of parents currently, or had previously, had significant concerns about their young person's mental health. For example, one parent recalled a time when her child had "teetered on the edge of clinical depression".

The majority of parents believed their son or daughter did feel able to "open up" to them. Indeed, most believed they were their children's only source of emotional/mental health support. The young people's own reluctance to use professional support was recognised as a barrier to accessing help.

Emotional well-being: how can the A-T Society help?

A handful of the young people we interviewed were aware of the counselling service which the A-T Society provides. None had used this service and no interest in this source of support was expressed during any of the interviews. However, this, in itself, is not surprising given the lack of knowledge and understanding of this service.

It is important to note, however, that the A-T Society does play a hugely important role in supporting emotional well-being by facilitating connections between young people with A-T, and providing opportunities for young people to spend time together. This issue was discussed further Section 4 (Friends and social networks).

Indirectly, the support the A-T Society gives to assisting young people with A-T to have rich and rewarding lives also supports positive emotional outcomes.

6: Mobility and independence

As we reported in an earlier section, having meaningful daytime occupations was a key element to a good quality of life. To that end, the young people were taking part in a wide range of activities or using day services. Having a means of getting to these activities and services is clearly essential.

Those we interviewed who were independently mobile, either within their home and/or outside, valued this highly. Manual and electric wheelchairs and walkers enabled independent mobility in the home, provided that the home was wheelchair accessible in terms of width of doorways and space. Electric wheelchairs and scooters enabled the young people to get out and about independently outside the home. Self-propelled wheelchairs had limited use here because of the effort required to use them.

Only a few mentioned that they regularly used public transport. Thus lifts in parents' and carers' cars, and more unusually, friends' cars were the main way the young people travelled around or took longer journeys. Parents noted that dependence on them or others for transport restricted the activities the young people could participate in.

It was very clear from the young people's accounts that being able to go out and about without being dependent on another for a lift or assistance, whether simply to 'take a stroll', to run an errand or to enable them to get to an activity, was a very pleasurable aspect of their lives. A number of parents commented that their young person's ability to move about locally by themselves had helped their sense of belonging and inclusion in their community.

Those not independently mobile, inside and/or outside of their home, typically regarded this as a key priority for change in their lives.

A number of young people were waiting for a motorised wheelchair or scooter, or for their current model to be upgraded. Here delays in provision of equipment or a long period of waiting for assessments were common experiences. Accessing funding for wheelchairs/mobility scooters was a significant issue for some families. Storage of large motorised wheelchairs or mobility scooters could be another difficulty.

A couple of young people aspired to learn to drive and have their own car. For these young people, being able to drive was viewed as enabling even greater independence and also

increasing work opportunities. A small number of others reported this was not something they would be able to do due to problems with their sight. However, many did not identify this as an aspiration for their lives.

Mobility: how can the A-T Society help?

A number of young people had benefitted from grants from the A-T Society which had supported the costs of motorised wheelchairs and driving lessons. This sort of support was highly valued. It is important that all families are aware of the financial support available as a lack of money was identified as a barrier to some young people 'upgrading' a motorised wheelchair, or getting one for the first time. There may also be role for the A-T Society in supporting families' negotiations with wheelchair services and also providing information about other grant making bodies.

7: Opportunities for independence and living independently

Being in control of day to day life and decision-making are fundamental aspects of independence.

I'm quite independent, that's important to me.

The young people strongly disliked and resented being treated as being unable to make choices and decisions, or not being consulted about something which affected their lives. Examples we heard included the way they were treated by members of the public and carers.

Sometimes people think automatically, "She's disabled so we make decisions for her."

The opportunity to be independent, if only for a limited time, also emerged as one of the reasons why the young people enjoyed their stays in respite care, hospices and holidays away from the family.

Basically you get to do what you want really....like you don't have to do certain things.

Equally, the young people valued parents' efforts to give them some independence whilst still living at home. Indeed, there was no sense in any of the interviews that the young people felt constrained by their parents.

Like mum and dad don't put restrictions on me. I can go out, like, until 2 o'clock in the morning if I wanted to.

Those who had attended residential college identified the independence this afforded them as key benefit. For some, it served to outweigh negative aspects of college life, such as limited academic opportunities.

College was amazing. I loved the independence.

I enjoy living at college because I'm pretty independent here.

A key issue for those who had been away to residential college was the return to the family home. This could prove to be a difficult adjustment both for the young people and their families.

Moving out of the family home

Only a handful of young people we interviewed had moved out of the family home. They were all very positive about this move, enjoying the sense of independence.

I feel that I am very independent. I love being independent, I really love it. I have my own space and, like, I do things by myself.

However, the loss of company associated with the move from living with family members to being alone was acknowledged as a downside. Frequent contact with family and neighbours had helped to overcome this.

Among those who were over 18 years and living at home, expectations that they would be able to move out of the family home, to live independently or in supported housing, were low even though this was something some aspired to, or were at least considering.

Well, I'm always hoping for that [a move into supported housing] but I don't think it's going to happen any time soon.

Sometimes I think to myself that I want to live on my own....and that I can manage on my own.

The barriers to making this move included: a perceived lack of options and opportunities; it not being something which has been suggested or raised with them; financial costs/affordability; and confidence about managing responsibilities and tasks of living independently of family.

I'd say I would like to leave home. Sometimes I think I would like to leave home but sometimes I think that I wouldn't. With the money that I get, I mean, I could afford the bills and food and everything but I wouldn't be able to go on holiday, which I love, and stuff like that. On balance I think it's OK at home for now. I suppose it's just me being the age I am....you would like to think you would leave home by now.

Independence: how can the A-T Society help?

A lack of information, advice and support in planning for and achieving moving out of the family – either to supported housing or living independently – emerged as a barrier to young people achieving this outcome.

8: Money

Most of the young people were able to describe the benefits and allowances they received and the way their carers, day and respite services were funded or paid for. Parents were typically involved in supporting the young people to manage social and health care budgets. None of the young people we interviewed reported feeling that they did not have enough money. A lack of money was not identified as a barrier to improving the different aspects of their lives. Indeed, the level of financial support they received through benefits was described by one making them feel “well looked after”.

For those over 18 years, having benefits paid directly to them engendered a sense of independence. As one parent noted, “it means he has money in his pocket”. Learning to manage money was something that parents viewed as an important milestone towards adulthood.

It is important to note, however, that some parents were concerned about the household income. Instances of a drastic reduction in the overall family purse caused by changes to benefits at 18 years were reported. A lack of advice and support appeared to be a major contributory factor here. In some cases parents were reluctantly working although deeply concerned that this meant their son or daughter was spending a lot of time at home without company and unable to get out and about.

Crucially, although money was not identified as an area of their lives which the young people regarded as a priority for change and improvement, during the interviews almost all described an unmet need which could be resolved by having more money. All these concerned ‘one-off’ expenditures, as opposed to meeting the costs of routine ‘items’, such as participating in activities (for example, gym sessions, clubs) or pursuing interests. For example, a number of young people reported their computers or laptops were not working but they could not afford to buy a new one. Or, they had stopped using computers because of access issues (suggesting they had not had access to adapted machines). Motorised wheelchairs or scooters were other high cost items which some reported being unable to afford. Finally, holidays and weekends away were very important to some of the young people and the number of trips were constrained by a lack of money.

Covering costs: how can the A-T Society help?

Most of the young people we interviewed had benefitted from a grant from the A-T Society. Whilst there was general satisfaction with the level of benefits and allowances, capacity to meet one-off, high cost items was limited. Having to delay purchases of such items (for example, computers, mobility equipment) inevitably impacted on young people's quality of life.

A concern raised by the young people was that, in applying for a sizeable grant from the A-T Society, they may be "draining the Society's finances" and not leave sufficient funds for others. Parents also reported finding it difficult to ask for financial help from the A-T Society.

We noted that all the young people we interviewed appeared to be in receipt of all their entitlements, suggesting that the work done by the A-T Society to support families in this is effective. However, raising awareness of issues around planning for changes to benefits at transition – which can have a significant impact on household income – may be an area to address further.

9: Health care

This section is concerned with health care. Here we combine both young people's and parents' accounts because this was not a topic that the young people chose to dwell on in their interviews. The interviews with parents, however, yielded more detailed information. Overall, the young people appeared quite neutral about their health care. Some had chosen to stop attending, or had never attended the clinics at Papworth or Nottingham. This was because the young people did not identify any positive benefits from their attendance, instead the clinics were seen as benefiting the doctors who were interested in researching the condition. Parents of these young people agreed and supported this decision.

I stopped going because I didn't want to be a guinea pig anymore.

One or two parents reported they had decided not to take-up the offer of an appointment at the Nottingham or Papworth clinics. Geographical distance, and the toll this would take on the young person, was the primary reason for this decision. However, these parents expressed surprise that they had never been re-contacted or received any information about A-T from the clinics.

Those attending the Papworth or Nottingham clinics did not offer much comment about their experiences of using them beyond seen them as offering their son or daughter "a good check-up". Attending a clinic was viewed as tiring, boring as well as, sometimes, quite stressful for the young person.

A common area of concern or unmet need, reported by the young people and parents, was the loss of physiotherapy resulting from the transfer from paediatric to adult health care. Almost all those who had transferred to adult health care reported losing physiotherapy at that point.

It seemed that the level of medical care and monitoring varied quite considerably between the young people, particularly once they had transferred to adult health care. Thus some were being seen routinely by consultants in local hospitals, and these were perceived as 'holding their case', whilst others were not. Likewise, for some the GP was regarded as 'holding their case' but for others contact with the GP was very spasmodic. Parents' accounts confirmed and expanded these points. Their reports suggest the quality of care and support available from GPs was enormously variable. Some parents had no confidence in their GP whilst others reported them as very supportive, offering to make home visits as and when necessary. Only one family identified the Papworth clinic as holding their young person's case.

There was also evidence of a lack of consistency in the way cases held by an adult specialism, typically neurology, were managed. Some parents reported that their young

person was monitored routinely by a local consultant. Others said the son or daughter's case was not kept open, with a new referral to the consultant required when a health issue emerged. A number of parents also expressed concerns about the level of knowledge or expertise in A-T held by consultants in district hospitals.

Finally, a few parents also mentioned the change in approach between paediatric and adult health care in terms of the parental role in appointments quite unsettling. In contrast to paediatric clinics, staff in adult clinics engaged directly with the young person and parents could feel excluded. Adult practitioners were also described as more 'severe' and 'blunt', which took getting used to.

Health care: how can the A-T Society help?

There were very mixed feelings about the Nottingham and Papworth clinics; the perception that these clinics were for the benefit of doctors or for research purposes only was the predominant reason for ceasing to attend.

Areas of improvement identified by families were:

- to consider how clinics could be in contact with, and provide information to, families unable to attend the clinics;
- to consider ways to make clinic appointments less boring and stressful;
- to consider whether clinics can coincide and be located near A-T family weekends.

We would also note that addressing families' understanding of the purpose of the clinics may be worthwhile.

Families did not identify the A-T Society as having a role in supporting their use of local health care services. However, we would note variable practices in the management of A-T by adult health care practitioners. In addition, information to help families prepare for the transfer from paediatric to adult health care may be something the A-T Society would like to consider.

Finally, it would seem that the A-T Society could, on a case by case basis, have a role to play in increasing GP's awareness and understanding of the condition.

10: Young people's views about the A-T Society

All the young people we interviewed were very positive about the A-T Society as were the parents. They recognised, and were very grateful for, the support it had provided to their family in terms of information, emotional support to parents, and grants. Having an organisation specific to A-T was seen as very important and what made the A-T Society such a valuable resource and source of support.

A big thank you to them all for all the support they've provided!

They do a fantastic job: we're in debt to them.

They've always been there for me.

The young people's awareness of the services and support provided by the A-T Society

We asked the young people about what support the A-T Society provides and its other activities. The following were most frequently mentioned:

- the support provided by Kay;
- newsletters;
- clinics;
- family weekends and events/holidays for young people;
- research.

Only some knew that the A-T society provided grants to families. Similarly, not all were aware of the A-T Society website and Facebook account. Only a handful mentioned the counselling support from Helen: they were aware of this either because another family member had used this service or because of her presence at the family weekends.

The A-T Society and research

There were very mixed, and strong, views about the fact that the A-T Society contributed to research funding. Some, perceiving that their condition is not curable, could not see the point of medical research into A-T.

I'm not interested at all in research. Like I told you, if you've got A-T there's no cure for it. So I don't like it [research] at all...I'm not interested. I don't like being treated like a guinea pig at Papworth and stuff. I personally would like [more] holidays and weekends with A-T sufferers, but the Society is more focussed on the research. Sometimes I think, "What are they all researching?" because they've already said there's not a cure. So I don't really understand all this research and the involvement that the A-T Society has with it.

Others viewed it in the opposite way: that research gave hope of a cure if not for themselves but in the future.

I'm like the hamster...the guinea pig, but I know it's helping others....and I get a lollipop out of it!

In terms of finding out about the research the A-T Society was supporting, the young people typically said they used their parents to pass on information to them: either that reported in the newsletter/website or at sessions at family weekends. Their disinclination to access information about research directly stemmed from a perception (or direct experience) of presentations or writing would be complex and scientific and, hence, difficult to understand.

The following suggestions were made to improve young people knowing about research into A-T: to have a meeting just for doctors/researchers and young people at the family weekend; and presenters take care to make sure written information and presentations are understandable to people who are not researchers or doctors.

Sometimes it's a bit like gobbledygook!

I sit in with the adults now I am an adult. I sit with the adults and listen to what the experts say. But I think there should be session for young people... where we are told in simple terms they should make it more friendly for young people with A-T.

...so we can ask questions as well as parents. Like: What's going to happen to me? Am I going to stay as I am, or am I going to get worse?

The family weekends

Not all the young people had attended a family weekend. However, many had very happy memories of these events and looked forward to attending them: time with other families and the meetings were both seen as important and valuable.

We do enjoy them, like meeting people and stuff.

There was a slight sense that some who had been to a number of them were both 'growing out of them' and finding some of the sessions repetitive. A number requested that the Saturday afternoon activities could be more adventurous and 'youth/young adult-appropriate'. Increased opportunities to mix with other young people and for introductions/getting to know each other facilitated by "ice-breaker" type activities was requested.

They need to provide activities for all ages....something that 'older' people can do. In the evenings I'm just interested in socialising.

One of the main barriers to attending a family weekend was geographical location. For some, a very long journey was not a feasible option. Those living in the north of the UK requested that the weekend was sometimes held at a venue closer to them.

Now they all seem to be down South...it's a really long way to drive.

The events and holidays for young people

Many of the young people we interviewed had been away on a holiday or weekend with the A-T Society. As discussed earlier in this report, the opportunity to spend time with others with the same condition was highly valued. Doing activities with others with similar limitations supported by knowledgeable staff was appealing.

To go away purely with people with A-T, so you're looked after, people know about the condition so they're not judging you thinking "she's wobbly," would be really good.

To go away with people just with A-T... just to go away with people with A-T.

Negative experiences of weekends/holidays reported by young people related to one of the following:

- issues with carers at the facility. Most disliked being looked after by carers they did not know: they asked that either they could take their own carers to these events, or that there was an opportunity to meet the carers in advance;
- the activities on offer were not of interest to them or not appropriate for their age (i.e. too childish/teenager-y). For example, a number of the young men mentioned wanting to do quite risky, 'male' activities. Similarly, outdoor pursuits are not to everyone's taste.

In some cases, a negative experience meant the young person chose not to attend any future events of a similar nature.

It is also important to draw attention to the fact that some of the young people we interviewed acknowledged they were shy and found going along to new social situations very difficult; this was a barrier to them attending events. Certainly, being able to take a carer would resolve this problem. Equally, or in addition, finding ways to introduce (not necessarily face-to-face) the young people prior to the event may be worth exploring. One

young person suggested, in advance of an event, sharing information about the young people's interests as this would help the young people to identify those with whom they are most likely to have something in common.

People think I'm shy to start with, but I'm not shy. It's just I have to get to know that person, because if I don't know a person I don't go up to them and say "Hi!" I need to get to know that person two or three times and then I can warm to them and become OK.

Young people's involvement in the A-T Society

We asked the young people who they thought the A-T Society was for: parents and/or children and/or young people. The majority responded that they perceived it as an organisation for all these groups, though a few noted that, compared to children, young people and adults were less prominent or visible on the website and literature.

It's there to help everyone, to help us and our parents: it's helping everyone.

I think it's a good thing that it's for parents because if their children are diagnosed they obviously need support If you go on the website it still a lot for families...it's all photos of kids with A-T and not really focused on the adults.

Aside from actual events, the young people did not typically make contact with the A-T Society. It was the parents who typically interacted directly with the Society, albeit sometimes at the young person's request. Staff at the A-T Society, particularly, Kay were viewed very positively.

Some young people felt that the A-T Society should find ways to involve young people more in decisions about what the Society does and how it spends its money.

I think we should take part in decisions about where the money is spent... to make sure it's going towards something that will help young people.

We should be able to make decisions and we should also be allowed to ask questions and have someone listen to you as well.

Others, however, did not raise this as an issue. One young person noted the wider benefits to getting involved in the running of the Society in terms of boosting skills and confidence.

I think that by getting you involved it gives you more confidence anyway and makes you feel more a part of the Society.

A Youth Worker role?

Most of the young people knew of and liked Kay; they were grateful to the support they, and their parents, had received from Kay. They valued the fact the same person had been there to support them and their family from the point of diagnosis onwards. However, it was clear that parents had had much more contact with Kay and had a 'closer' relationship with her. This is evidenced in the very warm way many parents spoke of Kay.

Without Kay we'd be lost: she's been our rock!

However, some of the young people we interviewed, when asked about how the A-T Society might improve their support to young people, suggest having a youth worker. Where this idea was not raised spontaneously, the interviewer asked for young people's views on this. There was strong support for such a role. There were two main reasons for this. First, young people may identify more with a younger person, and find it easier to talk to them.

....cos s/he might have the same interests and young people might find it easier to talk to a young person's worker.

That would be good: to have somebody who is just there for the young person with A-T.

Second, a youth worker was perceived as having particular expertise in the needs of young people and young adults, including the services and other sources of support available for this age group, and how to support young people in, for example, getting work and achieving independent living.

I think it would be good to have someone who is more knowledgeable about young people with A-T. I know Kay is, but I do think it's good to have someone who would just come and have a chat with you, and make sure you're aware of all the help you can get, whether it's financially, socially.....just things like that.

11: Concluding comments

The My Life project set out to improve the A-T Society's understanding of lives of young people with A-T and how the Society can best support them. This report has presented the findings of this project: we have used numerous quotes from the interviews with the young people as they powerfully illustrate the findings from this study. They also serve to ensure the voices of young people stay 'centre stage'.

The findings from this study demonstrate how the different facets of young people's lives are inter-connected. Taking part in activities can be pleasurable and can also be a means of making friends, each also have an impact on emotional well-being. Similarly, participation in activities is dependent on transport or being independently mobile, and this can require having sufficient finances to purchase, for example, a motorised wheelchair. Having a job has the potential to increase financial resources as well as broadening social networks, and both these outcomes impact on emotional well-being. These examples illustrate these interconnections and highlight the crucial importance of a holistic approach to supporting young people with A-T. Whilst statutory services may be good at delivering support and care related to a specific need, having the support and expertise of an organisation which is concerned with all aspects of a young person's life adds another 'layer' of support for families, as well as providing services which may not be available from statutory agencies.

The report has focussed on seven areas of young people's lives:

- meaningful daytime occupation;
- friendships and social networks;
- emotional well-being;
- mobility;
- independence;
- money;
- health care.

There was no particular rationale for the order in which we have presented the findings related to these different aspects of a young person's life. However, we would point to the differences in the depth of data. All the young people particularly dwelt on the following areas of their lives: meaningful daytime occupation and friendships and social networks. Other aspects were emphasised, and highly valued, by some but less so than others. Parents dwelt more on issues related to health care and were also able to reflect on their young person's emotional well-being. For some parents, these were both areas of concern or difficulty.

Two characteristics of A-T present particular challenges for young people living with the condition, and their families:

- diagnosis follows a period of normal, healthy development and is followed by on-going deterioration;
- it is a very rare condition.

These two features of A-T permeated the young people's accounts and offered at least partial explanations for why certain areas of their lives were unsatisfactory. The fact that, within adult social care, physically disabled young adults (without learning disabilities) are a minority group is another very important explanatory factor.

The penultimate section of this report was concerned with reporting the young people's views about the A-T Society and their ideas and suggestions for how the Society could better support young people. The consistency of their ideas is noteworthy, as is their appreciation of the support the A-T Society has provided to them and their families to this point.

We note in the report that lowered expectations for their lives appeared to inhibit young people's aspirations. It is very important to bear this in mind when reading this report and considering its implications.

Finally, the sample of young people we interviewed had more young women than young men. We have tried, where possible, to draw out gender-related differences; however, this is a limitation of the research.

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