

# Evaluating the Tree of Life project: An innovative way of engaging children and young people with type 1 diabetes

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**Type 1 diabetes interferes in the lives of children and young people, interrupting relationships and impacting on quality of life. It can dominate the lives of teenagers, taking over their identity and leaving them feeling disconnected from family and friends. The Tree of Life is an innovative one-day group event for young people with diabetes aged 10–19 years. It enables young people to build positive views of themselves, with an identity separate from diabetes, thereby enhancing self-esteem and empowering them to feel it is possible to reduce the negative influence of diabetes in and on their lives. To date, 93 young people have attended 17 Tree of Life day events at University College London Hospital. Attendees state that the project has helped them to develop positive views of themselves and feel less isolated by connecting, learning from and sharing knowledge with others living with type 1 diabetes.**

Guidelines on the diagnosis and management of type 1 diabetes in children and young people in the UK state that young people with diabetes are at risk of greater psychological problems than other children and need psychosocial support provided as part of diabetes care (NICE, 2015). Adolescence is a critical period for building a stable identity and finding emotional independence. However, type 1 diabetes creates multiple psychosocial challenges during adolescence, with poor diabetes control leading to long-term complications. The daily demands of diabetes, including regular blood glucose testing, injections and monitoring of food intake to control blood glucose levels, can compromise the young person's quality of life.

Traditional “psychological” approaches are often rejected by young people and parents. These approaches can be seen as implying that problems are located within the young person or family rather than a legitimate expression of distress associated with a chronic condition. With this in mind, at

University College London Hospital (UCLH) we have adapted the “Tree of Life” from a project for traumatised children who had lost parents to HIV/AIDS (Ncube, 2006; Denborough, 2008).

## The Tree of Life project

These one-day group sessions use a narrative therapy approach which helps young people share problems in ways that make them stronger by connecting with their strengths, abilities, hopes and dreams, as opposed to just giving accounts of illness (Portnoy et al, 2016). Enhancing self-esteem and empowering and stabilising positive identity stories contribute to a positive patient experience and improved quality of life.

The Tree of Life project's objectives are to provide an opportunity for young people to:

- Meet others living with diabetes.
- Feel comfortable sharing experiences and the effects of diabetes.
- Develop positive views of themselves to increase self-esteem.

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## Article points

1. The Tree of Life is a project to reduce the negative emotional impact of type 1 diabetes on children and young people.
2. In the one-day group sessions, participants share their experience and knowledge of diabetes with each other and are encouraged to externalise the condition and not have it define who they are as people.
3. Feedback suggests that the sessions result in attendees feeling less alone and better connected with their peers, and with more positive views of themselves.

## Key words

- Mental health
- Peer support
- Psychosocial care
- Tree of Life
- Type 1 diabetes

## Authors

Author details can be found on page 14.

### Page points

1. Young people aged between 10 and 19 years are invited to attend one-day Tree of Life workshops at University College London Hospital, with separate events run for children and teenagers.
2. Young people who have already attended a workshop are also offered to become peer trainers for subsequent events.
3. Attendees begin the day by drawing their trees, with different parts of the tree representing different aspects of their lives, such as their background, skills, goals and important people.
4. Through narrative questioning, each participant then tells their personal story, using the tree as a guide.

- Learn about and share knowledge of living with diabetes.
- Position and confirm themselves as experts in their condition.
- Change their relationship with diabetes so it impacts less negatively on their lives.

The UCLH paediatric and adolescent psychology service has been running Tree of Life events for young people facing the challenges of diabetes, aged 13–19 years, since 2010. The project was extended to include 10–12-year-olds in 2013 following feedback from the adolescents that this would be a good idea for younger children.

### Peer trainers

Running these groups, we were struck by the young people's enthusiasm for the project and the sense of community that developed from spending a single day together. We wanted to capture this excitement by creating an opportunity for further service user involvement. We therefore began to invite young people who had taken part in the groups to come back and help us facilitate further days, describing their role as "peer trainers".

The objectives were for these trainers to contribute to the ongoing engagement, learning and experience of the other young people attending the Tree of Life workshops, as well as to develop confidence themselves through acknowledging their valuable contribution (White, 2007), which links with the narrative idea of people being experts in their own lives (Anderson and Goolishian, 1992). This has been a powerful process both for the young people coming to the groups for the first time and for the peer trainers themselves.

### The Tree of Life process

Separate Tree of Life one-day workshops are run for children and teenagers. Young people are informed about the groups by members of the diabetes team, including the diabetes nurses, dietitians, consultants and members of the psychology team. The project has also been promoted through leaflets, posters and information on the UCLH diabetes website, which has led to self-referrals. Following expression of interest from healthcare professionals, parents or the young people themselves, a member of the

psychology team telephones all the participants to invite them formally to the day and to give more information.

Throughout the course of the projects, we have found splitting the younger group according to primary and secondary school years has helped with group connections and engagement. We now offer a Year 6 group and a separate Year 7–8 group. As the Tree of Life facilitators do not have a medical background, to help with diabetes self-management throughout the day, we liaise with parents and have a pre-planned lunch, and diabetes nurses attend the day or come in during break times and lunch to help out. To date, all the 13–19-year-olds have looked after their own diabetes and have not required the help of the diabetes team.

Between six and eight young people attend the workshop, along with two peer trainers and two facilitators. Age-appropriate ice breakers begin the day, to engage the group and help people to feel comfortable. The peer trainers are an important part of this process and often take a lead role in these ice breakers. The four parts of the Tree of Life project (Ncube, 2006) then make up the rest of the day.

### Part 1: Drawing and telling the Tree of Life story

This involves young people drawing their trees, using different parts of the tree as a metaphor for the different aspects of their life and identities. The different parts of the tree represent the following aspects:

- Roots: The young people's background, culture and family history.
- Ground: Their daily lives.
- Trunk: Their skills and abilities.
- Branches: Their hopes and dreams.
- Leaves: The significant people in their lives.
- Fruits: The gifts they have been given by others.
- Flowers: The gifts they have given to others.

These are written up in an example tree to act as a guide for the young people (see *Figure 1*).

Through the use of narrative questioning, an interviewer then asks each young person in turn to tell their story using their tree as a guide. The interview strengthens the preferred identity story

(White, 1995) by weaving a richer story through the following methods:

- Inviting and elaborating storying of skills, abilities and hopes (e.g. Tell me more about this).
- Historicising these skills, abilities and dreams (e.g. How long have you had this ability? Where does that dream come from? Who taught you that?).
- Bringing these into relationships with others (e.g. Who notices this skill? Who shares this with you?).

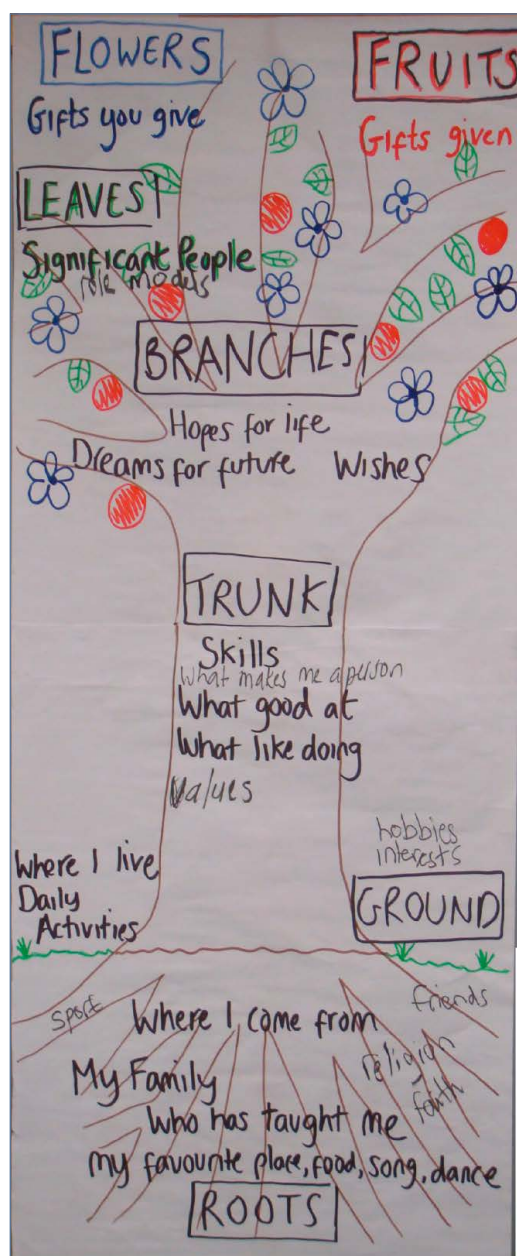


Figure 1. Tree of Life template to act as a guide for young people. Image courtesy of Dr Glenda Fredman.

- Connecting these to significant people (e.g. Who supports you in this now? Who makes it possible for you to do this?).

The other young people in the group, alongside the peer trainers, are invited to “witness” each other’s life stories through listening out for what they have learned from the young person and any qualities they have appreciated about them. These are written on “fruit” stickers while the person is telling their story and are then fed back and offered to stick on the young person’s tree at the end of the interview. This connects to “outsider witnessing” practices, which help to further reinforce people’s identity stories (White, 2000; Carey and Russell, 2003).

The peer trainers model this whole process first by being interviewed on their own tree in front of the group, with the other peer trainer and facilitator giving them their fruits.

### Part 2: The Forest of life

The young people then “plant” their trees together, displaying them on the wall to create a forest. The forest is a powerful metaphor connecting the young people with each other, creating a feeling of support and community. The peer trainers invite the young people to look at the forest in order to look for both similarities and unique qualities. This helps to provide a safe place to stand before they start to look at the “Storms of Life”.

### Part 3: Storms of life

Storms of life are introduced to the group, first considering how storms affect trees and then thinking about how they affect young people in general. Diabetes is then introduced as a specific storm, and young people share stories about the effects of living with diabetes. This helps to externalise diabetes and separate it from their identity (White, 1988) so that, instead of seeing themselves as “Diabetic”, they see “Diabetes” as a storm they face in life that brings with it other storms. Viewing diabetes as separate from their identity empowers young people to feel that it is possible to reduce the influence of the condition on their lives (White and Epston, 1990).

Young people are then asked about how they have responded to the effects of diabetes and how

### Page points

1. By telling their Tree of Life story and “witnessing” those of others, participants are encouraged to discover their own identity.
2. Once they have all told their life stories, participants “plant” them together to create a forest, in order to reinforce the sense of support and community. Comparing their trees with others in the forest helps to identify both similarities to other people with the condition and the participants’ own unique qualities.
3. The effects of “storms”, including diabetes, on the forest and the individual trees are then discussed, with the aim of establishing diabetes as something external and separate from participants’ identities.

### Page points

1. In the final part of the workshop, participants create and hand out certificates detailing the skills and abilities, hopes and dreams, and important people they want to acknowledge. This is designed to reinforce positive views of themselves.
2. A total of 93 young people have attended Tree of Life events at University College London Hospital since July 2010. Feedback has been very positive, with the peer trainers receiving particular praise.
3. Participants have stated that the workshops promote a feeling of togetherness and community, and provide an opportunity to bond with and learn from others with type 1 diabetes.

they manage their condition. This enables them to offer their specialist knowledge and ideas, and allows us to capture their wisdom, recognising that they are experts in their own lives (Anderson and Goolishian, 1992).

### Part 4: Certificates and celebrations

The young people then create individual certificates detailing the skills and abilities, hopes and dreams, and important people they want to acknowledge, using what they have written on their trees as well as from the fruit stickers others have given them. These are read out and presented in a ceremony at the end of the day, with parents and members of the diabetes team present. Showing certificates to others creates further opportunities to reinforce positive views of themselves, linking to the narrative intention of “spreading the news” (Freedman and Combs, 1996).

Prior to the award ceremony, young people are invited to participate in a group interview about their experience of the day to generate feedback, placing them as experts in shaping future projects. The evaluation below has been based on this feedback. Young people are also phoned 2–4 weeks after they have taken part in the project to ask about any further effects of the Tree of Life event on living with diabetes.

Following the Tree of Life day, thank-you letters are sent to each of the participants and peer trainers, in line with narrative principles, as an appreciation of the part they played in the day and to further reinforce their identity stories by acknowledging the skills they brought to the day. We also connect these skills to attributes that we are looking for in peer trainers and highlight how attendees can become peer trainers if they are interested.

### Results and evaluation

A total of 93 children and young people (60 female and 33 male) have attended 17 groups (12 adolescent groups and five child groups) between July 2010 and September 2016. The project now has 21 peer trainers and has run yearly peer training day events since 2013.

Data from the feedback interviews at the end of the days have been transcribed and analysed using thematic analysis. The data were re-read by

different team members to ensure the themes were grounded in data and supported by exemplary quotations. There were no differences that emerged between age groups; thus, all data have analysed together.

Two superordinate themes emerged from the data, which link directly to the objectives: connecting with others and building a positive view of the self.

### Connecting with others

Young people described the Tree of Life project as very powerful in “*how it links everyone*”, enabling them to “*feel part of a group*”. The Tree of Life days provided an opportunity for “*meeting other people with diabetes*” and “*to talk about it without people saying ‘what’s this?’*”. The young people enjoyed “*relating to other people with diabetes*” and described the day as a chance to “*let it all out – not like you go all emotional and cry; you talk about it... with people who understand*”.

Within this overall theme, there were three master subthemes, as follows.

#### From isolation to inclusion:

##### A feeling of togetherness

Young people expressed that they feel isolated by diabetes and “*feel like the only one*”. The feedback described a shift from isolation towards inclusion through attending the project: “*Sometimes it might feel like you’re the only one doing it, but there are other people*”, and “*I’m not the only one with diabetes... you’re not alone, if they can do it so can you*”. The “*Feeling of togetherness*” and acknowledgement of “*How we are all similar but different in our own way*” was a shift recognised as a result of the day.

##### An open space to share experiences

The Tree of Life day was seen as an open space for “*sharing experiences and wisdom*” and “*sharing views with other people*”. Attendees explained that they valued “*reflecting on other people’s beliefs and how they cope with diabetes*”.

##### Learning from each other about living with diabetes

The participants valued “*learning different techniques, seeing different people’s view on it*” and

described the sessions as “a really good flood of knowledge”. Young people saw themselves as experts able to “learn from each other’s experience” and to “think about what you do and others do to cope”.

The peer trainers received fantastic feedback: “I really liked it, another person who is older than us but has diabetes”. The young people gained “ideas about diabetes”. In addition to providing expertise, peer trainers facilitated engagement, allowing attendees to “show older people how you are dealing with it”. They also “had a chance to learn from us even though she is the teacher”, and attendees appreciated “being able to relate to someone with diabetes who is in the teaching seat”.

### Building a positive view of the self

The Tree of Life project achieved a shift from unhelpful comments such as “you’re the diabetic one, right?” to enable attendees to “look at yourself from outside” and examine their qualities, facilitating a positive view of the self: “It’s good knowing you can be an inspiration to other young people”.

Within this theme, there were three main subthemes.

#### Focusing on my qualities

The project helped young people develop positive views of themselves and increased self-esteem. The young people said, “I like that we were focusing on one another’s qualities, not just diabetes” and described it as an opportunity to “find out about self – build confidence”. They began to develop a positive identity: “lots of creativity and diverse talents” built on by others and a realisation that “I can have big dreams like normal people”.

#### Separating myself from diabetes

Separation of diabetes from their identity helps young people develop a positive view and a chance to develop a different relationship with diabetes (“Storms are always temporary”) for it to have less impact on their lives. The project was described as a “way to express your feelings, step back and [...] realise diabetes is not everything”. Attendees reflected that the day “helped me in learning who I was without diabetes. I often just feel like a diabetic and there is nothing else to my personality, but this has helped me realise that there is so much more to

me”. In other words, “I came in as a diabetic and left as a person with diabetes”.

#### Empowerment

The project helped attendees to develop a positive view of themselves, enhance self-esteem and, ultimately, give a sense of empowerment: “When we did the trees it made us realise we can do a lot of things and diabetes will not stop us when you think about your skills”. The young people’s relationship with diabetes changed as a result of the day: “Having diabetes makes you want to fulfil your life more than before”, and “Diabetes comes into so many areas of life... if you can conquer that you can do anything”.

#### Telephone interviews

Since 2014, telephone interviews have also been conducted with the participants 2–4 weeks after attending the group, with the intention of finding out if there have been any further effects from the project. In particular, questions have focused on the effects on diabetes care, including questions such as “has the group affected how you think or feel about diabetes?” and “what have you been doing differently as a result of the day?”.

Data from these phone interviews have also been transcribed and analysed using thematic analysis. Similar results fitting into the themes previously described were elicited; however, two further themes emerged.

#### Responding to negative attitudes about diabetes

Young people reflected on the effect of the Tree of Life day on how they have responded to other people’s attitudes towards diabetes: “I don’t let it bother me if people say horrible things; I don’t pay attention to it any more”, and “I don’t react to what people say”. Young people instead felt that, having met other people and spoken in a group about diabetes, they were able to discuss this with other people (“I’m not afraid to talk about diabetes any more”) and that the group “encourages you to be more confident about diabetes and stand up to bullies”.

#### Improving diabetes management

Some participants also reflected on the project’s impact on how they were looking after diabetes

#### Page points

1. The workshops are also reported to improve participants’ confidence and self-esteem, and the young people leave with a more positive view of their condition.
2. Telephone interviews conducted several weeks after the workshops have revealed other changes, including improved interactions with people who do not have diabetes and improved confidence to self-manage the condition.

### Page points

1. The Tree of Life is a way to help young people who are struggling with the challenges of diabetes but who do not qualify to receive more intensive psychological therapy.
2. However, the one-day workshops require a significant amount of planning and preparation, both in enrolling young people and in facilitating the workshops themselves.
3. The workshops require staff with a knowledge of narrative therapy and the Tree of Life itself. Training in these approaches is available.

in a different way, including *“looking after myself more, checking bloods regularly”, “thinking more about blood glucose testing” and “trying to manage when high”*. They reflected on what made this possible, finding that *“looking at diabetes differently helps me to think about what I can be doing to make things better” and “it helped me in the acceptance of the condition, and my diabetes care has improved”*. Other young people spoke about the effect of separating themselves from diabetes, which enabled them to talk more to others and how this helps in their management: *“Realising that diabetes is just one part of me helps me in feeling more confident in talking about diabetes on a day-to-day basis. I can now mention when my sugars are low to my friends rather than hiding it”*.

### Conclusions

These results highlight the positive effect that the Tree of Life project has had on the participants in feeling part of a group and connecting to others, as well as building more positive views of themselves. This links to the objectives and narrative intention of strengthening young people's identity stories, lessening the negative influence of the condition on their lives and creating connections and a sense of community with others (White, 1997; Fredman, 2013). Another powerful effect following the group session has been that some of the participants reported a positive change in how they manage their diabetes.

The Tree of Life project has reached out to young people struggling with the challenges of diabetes, but also to those who do not reach the threshold for more intensive psychological therapy. The project has also had an impact on young people and families' engagement with the service. Young people said they were more open to referrals to psychology for quite serious problems that they had not wanted to address before the group session. Medical staff are also appreciative that we are engaging young people, and it has started creating a sense of a community of both staff and young people in our diabetes service.

### Study limitations

There are limitations to consider when reflecting on the outcomes of the workshops. The participants all agreed to come along and were,

therefore, a self-selected group. The qualitative interviews were also conducted in a group at the end of the day and are thus subject to a degree of bias. No objective, quantitative outcomes have been collected. Although there are reports of improved diabetes management, the intention of the project has not been to directly affect HbA<sub>1c</sub> levels, and it would be a challenge to measure this independently of all the other things that are happening in young people's lives. In addition, with the exception of the peer trainers, we have not followed up over the longer term to see whether the above themes and positive findings have continued for participants.

### Reflections on the project and future directions

We have established an annual Tree of Life programme comprising four groups per year, plus one yearly peer training programme, which are all run in the school holidays and half terms. Each day takes a significant amount of planning and preparation. This involves an assistant psychologist sending out leaflets, calling up interested participants, sending out confirmation letters, arranging a suitable room with equipment and pre-planning lunch with younger participants. Two trained facilitators are also required for each day, and we have been lucky enough to secure funding to provide lunch and snacks for all participants.

The peer trainers have been pivotal in the project, being role models for the young people, helping to facilitate the engagement of the group and allowing young people to feel comfortable. There has been very positive feedback from participants about the peer trainers as well as positive outcomes for the peer trainers themselves, and we have therefore developed a formal training programme for peer trainers.

Delivering the Tree of Life programme requires training in the approach and an understanding of narrative ideas. We have thus developed and have been running narrative group training workshops on using the Tree of Life with adolescents since 2014. These workshops are available to all professionals in diabetes services throughout the UK, as well as professionals working with any chronic health condition. The peer trainers take part in this training and have also helped us

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co-facilitate presentations at conferences about the project.

We are continuing to develop our peer training programme in order to think about how to keep people connected to the project and encourage a sense of community, as well as how to invite new participants – especially teenagers – to take part in the project. We are developing a short video for participants and staff about the day and are also starting a blog on the UCLH website with information about the day and posts from previous participants and peer trainers. We are very excited to continue developing this project and to think about using this approach with other young people in our paediatric service who are living with other challenging health conditions. ■

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### Tree of Life workshops

These workshops include a review of narrative theory, an opportunity to experience the Tree of Life as a participant and a chance to practise narrative questioning. There also is an opportunity for healthcare professionals to understand the process of running these groups and think about how to take these approaches into their practice.

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