

Helping young people with kidney disease to transition

Young people with kidney disease face numerous challenges in their everyday lives. The British Renal Society's regular transition events and annual weekends away for young people with kidney disease give attendees a chance to enjoy a sense of community, build relationships and push themselves to achieve their goals, with far-reaching positive effects.

■ kidney disease ■ transition ■ young people

The British Renal Society Special Interest Group in transition has been in existence for 3 years and is supported through a grant from Kidney Care UK and the Association of Renal Industries.

The main purpose of the group is to share good practice and organise events to improve peer support and self-management skills for young people throughout the UK and maintain a network or community of professionals, as well as young people, to ensure this happens. This has been achieved by:

- Organising a regular transition event for health professionals and young people with kidney disease
- Organising an annual weekend away for young people with kidney disease, supported and facilitated by key worker roles.

The benefits of a group of key workers and health professionals working together with the young adults themselves have been hugely significant in planning services and events. Several Trusts now have a transition lead, supported by a key worker, such as a specialist nurse or youth worker. For an up-to-date list of transition leads and keyworkers, please contact rachel.gair@renalregistry.nhs.uk.

As part of this work, in September 2017 a group of keyworkers took 78 young adults (aged between 18 and 30 years) and living

with kidney problems away on a residential break to Ilam Hall in Derbyshire, funded by the charity Kidney Care UK.

Aims

- To offer young people respite from the day-to-day challenges of living with kidney disease
- To provide an opportunity to meet other young adults and create informal peer support networks
- To offer the opportunity to learn new skills through facilitated workshops and activities.

Ilam Hall was chosen as the location to enable young people with disabilities to attend, as well as to enable us to increase the capacity from previous years. The venue is a youth hostel set in several acres of grounds, which provides full catering as well as different areas to facilitate and deliver the weekend's programme.

Structure

The residential trip ran for 3 nights: from Friday afternoon through to Monday. Outdoor activities were provided by an external company that has assisted with the event in the past and comprised kayaking, rock scrambling, survival skills and rock climbing. On the Sunday morning several workshops were held based on feedback from the young people. The workshops focused on various issues, including:

- Applying for jobs and what to put on applications regarding kidney disease
- Diet and exercise
- Confidence building.

We believe the workshops to be an extremely important part of these weekends, as they challenge how young people view

themselves and give them important information about their conditions in an informal manner. The workshops help young people to develop new coping skills and even support them to think about applying for work or training. The potential benefits of these workshops are really exciting, and they hold an important place on the weekend's programme.

As well as this, other, more informal activities were on offer to the young adults throughout the weekend. This included a quiz on the Friday evening, produced and organised by one of the young adults. Free time was an opportunity for the young adults to mix with each other, as well as with the key workers. This provided time for peer support and the sharing of experiences. The weekend culminated in a masked ceilidh on the Saturday evening, which provided great hilarity.

The young adults came from 32 different units across the UK: 33 attendees were female and 45 were male. The breakdown of young adults across modalities was as follows:

- 40 transplants
- 27 haemodialysis, with 3 of those on home haemodialysis
- 1 peritoneal dialysis
- 10 with chronic kidney disease of varying levels.

Some 40 of the young adults had attended at least one weekend previously, whereas 38 young adults were attending for the first time. Facilitating the weekend were nine keyworkers, made up of youth workers, nurses and a nephrologist, as well as three additional members of staff, including volunteers and a British sign language interpreter.

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Activities

Activities were an important part of this weekend for the young people. Although far from being the main highlight of the weekend, the activities provided an important chance for the young people to feel empowered, to realise that they are still capable of being active and challenging themselves in a safe environment. The activity providers we chose were there to support the young people to overcome any barriers to taking part in these activities, which we feel they achieved brilliantly. The activity providers also encouraged the young people, challenging them to overcome their fears and achieve something they may not have thought they were capable of.

The change in mindset this gave the young people was remarkable, and attendees returned from the trip with a new vigour and thirst for life, and viewed themselves and their condition in a much more positive light as a result. Importantly, this change in mindset can have a positive impact on a person's overall health, for example, some young people's compliance with treatment regimes improved post-trip, and some have gone back to education, employment or training. More research needs to be conducted to fully understand these benefits.

The activities not only provided an important opportunity for young people to overcome their own barriers to participation, it also gave them a chance to see other young people who are at various stages of their illness challenging themselves and achieving their goals. It is so positive for a young person who is pre-

dialysis to see someone on dialysis or who has had a transplant still excelling at and enjoying these activities.

Feedback

Feedback from the event was hugely positive. James, a 26-year-old male, who attended the trip for the first time, gave the following feedback:

'To say this activities weekend was enjoyable is simply an understatement. I found this weekend to be quite special. Dialysing three days a week means I don't get to go out as much as I'd like anymore. The treatment is so invasive and for those (like myself) who tend to internalise their health issues, it is near impossible to stay active and sociable. Especially where I am receiving treatment, in a centre where the average age is 45 and over, I find it difficult to connect with those at the unit. The weekend, however, offered me a lifeline. Seeing people closer in my age "struggle" with similar conditions was not only insightful, but reassuring. There is a real sense of family and togetherness within the group and that has continued even now, a week after the weekend. I am happy and proud to be part of such a compassionate and courageous kidney family!' (James, 26)

Future plans

A similar event is being facilitated to take place in October 2018. At the last count, 100 young people have signed up to participate through their units, the Young Adult Facebook page, or through National Kidney Federation and Kidney Care UK. The

weekend has been planned and coordinated by the keyworkers, alongside a group of young people, to ensure that it continues to adapt to feedback from previous years. This year we have had to hire larger accommodation with flexible facilities to suit all attendees, as the weekend becomes more diverse. We are immensely grateful to Kidney Care UK for their continuing support and funding of this weekend.

Sharing good practice, perspective and experience

The special interest group will be holding its second national meeting in Salford in 2019. Titled 'Improving services for young people: perspectives, practicalities and pertinence', the aim of the meeting is to bring together young people with kidney problems (and other long-term conditions) and the health professionals who plan care with them, to share their experiences and practice. The programme this year caters for everyone and can be accessed from the BRS website at <https://britishrenal.org/aboutus/special-interest-groups/>.

If you would like to register for the event or find out more details please contact rachel.gair@renalregistry.nhs.uk **JKC**

Further information:

'Improving services for young people: Perspectives, Practicalities and Pertinence', the second national meeting of the British Renal Society Transition Special Interest Group, will be held on Monday 28 January 2019 at Frank Rifkin Lecture theatre, Salford Royal Hospital, Stott Lane, Salford, Greater Manchester, M6 8HD



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