

Renal Young Adult Support Worker

Following an application from the Social Work staff at the NHS Lothian Renal Service, NHS Lothian Charity provided funding of £85,862 over 2 years from the Medical Renal Unit Fund and the Midway Trust Fund. The funding was used to pilot a role to address the high levels of social isolation and low levels of wellbeing reported by young adults aged 16–35 supported by the Renal Service at the Royal Infirmary Edinburgh. The funding was used to employ a full-time Renal Young Adult Support Worker to provide person-centred care. Sharlene Taylor was appointed in 2023 with a focus on improving overall outcomes for young adults living with renal conditions while they negotiate the transition from child to adult services.

Sharlene provides a programme of support to address crucial aspects of young adults lives, the work is both preventative and also reactive, helping young people overcome issues. It includes:

- 1-1 tailored emotional and/or practical support in person/over the phone.
- Financial support – support to apply for benefits or grants from third sector organisations.
- Support for young adults renal patients and their families at medical appointments and clinics.
- Projects and initiatives to promote peer support, relationship building and confidence such as a trip to Kidney Care UK residential weekend and the Great Scottish Kidney Kitchen Bake Off.
- Monthly Peer Support Group – a mixture of fun activities, information giving and sharing of experience.

This Impact Report presents just some of the activities Sharlene has co-produced with young people, and their impacts.

In 2 years Sharlene has had 100 referrals, providing varying degrees of support:

- 33 patients intensely supported
- 50% of those experience health inequalities
- 56% male, 44% female
- 55% pre dialysis, 15% on Haemodialysis (HD), 30% post transplant
- Supported 5 young people through transplant process (2 female, 3 male)



Sharlene, Young Adult Renal Support Worker

Living with a renal condition as a young adult

A diagnosis of Chronic Kidney Disease means that the kidneys do not work as well as they should. There are different stages of disease but in severe cases, it is likely to need specialist treatment such as dialysis or kidney transplant.

Research in the [British Medical Journal](#) states: “Young people with chronic conditions often face more difficulties negotiating the tasks of adolescence than their healthy peers...Chronic conditions in adolescence can affect physical, cognitive, social, and emotional spheres of development for adolescents, with repercussions for siblings and parents too.”

Sharlene has observed this in the young adults she supports. She explains: “Living with kidney disease is difficult. The condition affects every area of someone’s life and for someone just starting their adult life, a diagnosis of kidney disease can be crushing and a real loss of confidence. This is a time to be looking forward to becoming an adult version of themselves; things like making friends, finding love, being financially independent and securing employment. But, to many young adult patients, these life goals can feel out of reach. Once a patient is referred to me by a healthcare professional we work together to think about achieving their goals and improving their life.”



You no longer feel alone in the battle.”

– Young adult renal patient

Preventing health inequalities

Young adults have improved financial situation

Sharlene has observed many of her patients are not aware that they can apply for certain benefits or feel embarrassed asking for help so can miss out on what they are entitled to. Being assessed for benefits such as Adult Disability Payment (ADP – Scotland only) is especially challenging as a decision can take up to ten months. If the claim is rejected, more time is needed to appeal. This means young adults can have no income for several months and cannot afford life's basic necessities, like food and a safe place to live which can have a detrimental effect on mental and physical wellbeing. Sharlene supports patients to complete multi-page application forms which communicate the true impact of their kidney disease.

86%

of young adult renal patients reported their financial situation improved as a result of Sharlene's support



17 patients supported to receive Adult Disability Payment equating to £28,708.20 in benefits per year and £27,700 in backdated payments which opened up access to other welfare rights support

Young adults have positive destinations post school

Treatment for kidney disease is time consuming and can erode time for study. Hospital appointments and in-patient stays are often unpredictable and disrupt school schedules. Many young adult kidney patients feel unable to commit to furthering their education at College or University because of the unpredictability of their health condition and not knowing what the next few years might look like. When young adult patients secure work, employers often fail to recognise the need for minor workplace adjustment, like additional toilet breaks, because some of their disabilities are hidden. Gaps in education, training, and work experience can result in lower income for young adults, which in turn results in poorer wellbeing and health outcomes. To boost positive destinations, Sharlene delivers SQA-approved Youth Scotland Awards, providing young people with additional, future focused qualifications to enhance their prospects after leaving school.

86%

of young adult renal patients reported improved future options as a result of Sharlene's support



Sharlene attended my college interview with me and we chatted over some of work to carry out. I've now passed my HNC in childcare and she has talked me through some job interviews. She helped me gain volunteer work at the NHS and I'm now a play worker and do Therapets in the hospital."

- Young adult renal patient



I've really appreciated all the help Sharlene has provided, without her I would be struggling a lot with my future goals."

- Young adult renal patient



She helped me access numeracy course and volunteer work as well as introducing me to my world of work to create a CV so that I'm ready to apply for jobs."

- Young adult renal patient



Great Scottish Kidney Kitchen Bake Off

I was struggling with getting hours at work and Sharlene was able to get me a hardship grant, I was then able to buy myself essential items."

- Young adult renal patient

She supported me to sort out rent arrears. She called the council to help set up a direct debit otherwise I would be homeless."

- Young adult renal patient

Helped me to get ADP. I got backdated pay and now a monthly amount to support my condition... without her helping me I wouldn't have this."

- Young adult renal patient

Improving emotional wellbeing

Research in the [British Medical Journal](#) states: "Chronically ill young people often have lower emotional wellbeing than their peers. They may feel alienated from friends and frustrated by the demands of managing their health and navigating the transition from child to adult health and social care services. Frequent absences from school and a lack of participation in activities can result in social isolation." The Peer Support Group, events, and activities organised by Sharlene in partnership with the young adults address this.

86%

of young adult renal patients agreed they felt less socially isolated



Peer Support Group at bowling

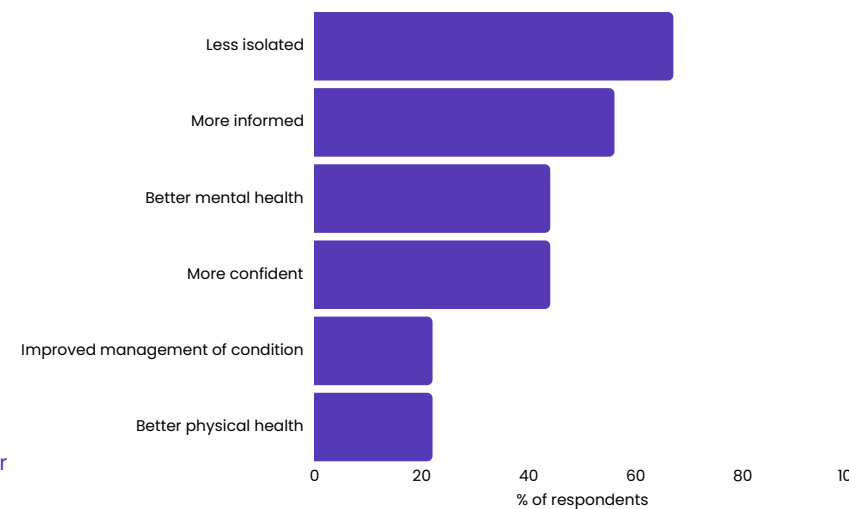
100%

of staff from the Renal Service reported young adult renal patients were less socially isolated

Young Adult Renal Peer Support Group

Peer Support Groups offer young adults the opportunity to meet other people in the same situation reducing feelings of isolation and increasing wellbeing. In a recent [international study](#), 91 % of chronically ill young adults reported that it was important to them to know other chronically ill young adults. Sharlene quickly identified this unmet need for young people in the service and started the Young Adult Renal Peer Support Group. She has since held 15 sessions with 128 attendances (patients attend multiple sessions, average attendance is 8 per session). The format is a mix of online, in person at the hospital and hybrid, which enables young adults who are feeling unwell to still participate. The group offers attendees the chance to share stories and learn essential life skills and information from invited experts. These sessions range from presentations by Citizens Advice Bureau and anxiety workshops to fun activities like bowling.

Impact on the young adult renal patients that attend Peer Support Group meetings.



After the meetings I feel more at ease as I feel I have been able to relate to others it then means I have less chance of social anxiety when I am out in public. My mental health has really improved since coming to the group."

- Young adult renal patient

Most of my friends don't know I have kidney disease, I don't tell them as I don't want them to change what they think about me so it's good to have this group and have friendships where I can be truthful about my disease. I am more relaxed and energised."

- Young adult renal patient

It's good to hear similar situations, I feel less lonely."

- Young adult renal patient

I feel included and that I have some close friends who are understanding. This group has been central to making me feel a little less alone."

- Young adult renal patient

The support from Sharlene has come at such a vitally important time for my son...he is learning how to do things for himself and having the chance to meet other kids his age going through similar things that he just wouldn't have had the chance to otherwise. He would have been very isolated."

-Family member

This patient has been very isolated but has joined in some of the group activities Sharlene has organised which has made such a difference to how lonely this patient felt"

-NHS Lothian Staff member

Empowering young adults to cope with their renal condition

Young adults have increased confidence to talk to healthcare professionals about their condition

The transition from child to adult services can mean parents are less involved in treatment and care. Chronically ill young people frequently experience low self-esteem which, along with other factors, can impact their ability to confidently engage with healthcare professionals resulting in poor attendance at appointments/clinics, misunderstandings, poor treatment compliance and ultimately worse clinical outcomes. Sharlene's support at appointments supports young people to build confidence and skills.

100%

of young adult renal patients agreed they are more confident to talk about their renal condition



Talking to Sharlene has enabled and empowered me to ask my renal doctor questions about my condition. She helped me ask questions, I have grown in confidence to do this by myself now.”

- Young adult renal patient



She is helping me feel more confident to find out about my condition as English is not my first language.”

- Young adult renal patient

92%

of staff from the Renal Service reported young adult renal patients were more confident to talk about their renal condition



I have had patients who didn't dare to ask questions about their health, now voice their questions confidently.”

- NHS Lothian Staff Member



Patients who have received support from Sharlene tend to become more confident when discussing their condition with me in clinic over time.”

- NHS Lothian Staff Member

Young adults are more informed about their condition

Kidney disease can be overwhelming for a young person. There is so much to learn and having to manage the requirements of life with kidney disease can be very stressful and frightening. For young adults moving into adult services, being informed about their renal condition is the key to shifting from simply receiving care to actively managing their health and becoming a partner with the medical team which Sharlene supports by giving patients the tools and confidence to do this.

100%

of young adult renal patients agreed they have a better understanding of their renal condition



Sharlene helped me understand what happened to my kidneys. She gave me the confidence to ask my consultant and came to clinic with me. She supported me to make a mood board about the things in my life I wanted.”

- Young adult renal patient



She makes me aware of some of the symptoms I may face so I know when they happen to speak about them.”

- Young adult renal patient

100%

of staff from the Renal Service reported young adults renal patients had a better understanding of their renal condition



Sharlene has been able to offer help to one of our dialysis patients who we felt was significantly impacted by ongoing health issues. I have noticed improvement in this young patient over recent months, particularly their ability to talk more freely about health worries and about their future. ”

- NHS Lothian Staff Member




Peer Support Group games night


Improving clinical outcomes

Improving transplant outcomes

Staff at the NHS Lothian Renal Service often have concerns regarding young adults' ability to cope and adjust to the life-changing impact of a renal transplant. The entire transplantation process, from waiting for a viable organ to surgery and post-operative care, can significantly impact a young adult's mental and physical wellbeing. The support provided by Sharlene, through both peer support and 1-to-1 sessions, directly addresses these challenges increasing the likelihood of successful transplants for the young adult patients.

 Sharlene has made a huge difference to the individuals that she works with which can be the difference between them making it through the waiting list for transplant and not."

- NHS Lothian Staff Member

 I was selected for transplant but it didn't go through, the first thing I did was contact Sharlene for emotional support."

- Young adult renal patient

 Sharlene encouraged me to keep a journal of my symptoms which I take to my appointments with the consultant and discuss. My symptoms are better managed now because we are all more aware."

- Young adult renal patient

Reducing readmission rates

Hospital readmission is a concern for young adult renal patients, often triggered by condition mismanagement, transplant complications, or underlying mental and physical illnesses. These admissions lead to poorer outcomes and increase healthcare costs. Sharlene addresses this by providing customised support that mitigates these risks, actively working to prevent readmission.

Less missed appointments


Several studies highlight that: "Younger age (18-29 age bracket) is a significant predictor of non-attendance for hospital outpatient treatments and specialty clinic appointments, even among those with chronic diseases." In this age group, socioeconomic status, mental health issues, transportation issues, poor communication, and scheduling difficulties contribute to missed appointments. Sharlene's attendance at young adults' appointments has improved engagement, curbed wasted clinical time from missed visits, and delivered better patient outcomes.

25%


increase in attendance at appointments in this age group at the NHS Lothian Renal Service (from the year prior to Sharlene in post)

 I used to miss some appointments as I tend to forget lots of things when I speak to my consultants and I just didn't feel confident to ask questions but Sharlene has attended appointments with me to ask those questions I might forget, so I feel so much more equipped to attend appointments now."

- Young adult renal patient

 We have better communication/links with the younger patient population now. They are more amenable to attending appointments and agreeing to treatment with the support from Sharlene."

- NHS Lothian Staff Member

 Much improvement since Sharlene in post. She links with the patients and they agree to attend appointments if she is able to accompany them."

- NHS Lothian Staff Member





Wreath making with Nature Ranger, Lou

Case study- Residential weekend provides peer support and fun!

A highlight of the service in 2024 was a weekend retreat to the Kidney Care UK's residential weekend for 18 to 30 year olds to the Mount Cook Activity Centre in Derbyshire. The event is designed to foster connection, build confidence, and provide a fun, supportive environment with activities such as zip wires, high ropes, kitchen workshops, music workshop and a fancy dress party. While Kidney Care UK covered the cost of the event places, attendees were responsible for their own transport. To remove this barrier, Sharlene requested £1,800 from NHS Lothian Charity to pay for transportation and t-shirts to build group identity.

Sharlene explains the importance of hiring the private minibus and driver: "While patients and their families were very keen on the trip, the proposed 8-hour journey involving two trains was a major source of concern, many of the young people worried about how to manage their medical condition on public transport, particularly issues like needing to use a toilet when required. For some, this was their first time travelling independently and away from home, so they lacked the confidence to take the train on their own. Furthermore, the cost of public transport presented a significant financial barrier for several families. Securing the bus solved these problems and provided an unexpected bonus: because many of the young people didn't know each other beforehand, the 8-hour journey gave us an excellent opportunity to build rapport and establish a strong group bond before we even arrived at the event. Without the bus, the trip simply wouldn't have been possible."


 Having our group together on the minibus made us more confident walking into the residential together."
- Young adult renal patient

 I wouldn't have been comfortable travelling on my own on public transport due to my illness so the bus made such a difference."
- Young adult renal patient

Impact on young people who attended the weekend

100%


of young adult renal patients that attended reported a BIG improvement in their confidence levels

 I had never been away from my family on trip before. It felt scary and overwhelming at first but once there and settled I grew in confidence."

- Young adult renal patient

100%


of young adult renal patients that attended reported an improvement (70% a BIG improvement) in how socially included they felt

 Because I have a hearing impairment I lacked confidence to speak to others. After this trip, I was able to speak to people that I would have never spoken to before."

- Young adult renal patient

100%


of young adult renal patients that attended reported an improvement (30% a big improvement) in their ability to talk to others about their renal condition

 Taking part made me feel like I'm not different whereas at home with friends I don't talk about my condition as it makes me feel different from them."

- Young adult renal patient



Attendees with the bus and t-shirts funded by NHS Lothian Charity

 The impact of this weekend was profound, seeing these young adults grow in confidence and form lasting friendships was truly inspiring. The support from NHS Lothian Charity made it possible for them to experience joy and connection, which are so vital for their wellbeing."

- Sharlene, Renal Young Adult Support Worker

Impact on staff and NHS Lothian's Renal Service

100%

of staff from the Renal Service agree (92% strongly agree) Sharlene's role complements the care young patients get from the unit (she provides support that medical NHS staff aren't able to provide)

100%

of staff from the Renal Service agree (92% strongly agree) Sharlene's role allows time to be spent with young patients that staff on the unit don't have due to medical priorities and tasks

100%

of staff from the Renal Service agree (75% strongly agree) Sharlene's support is specific to the age group and she understands the challenges the young people face when living with a renal condition

"I feel that we are now a more complete renal unit. Life as a young person with serious kidney disease is hugely challenging and I feel that, with Sharlene, we are now better at providing holistic, empathic and more effective care."

- NHS Lothian Staff Member

"This was a neglected area as it falls outside direct medical or social work care. Sharlene's work adds genuine value and holistically knits all care together for the benefit of young people. It's difficult to say how we managed before she was in post."

- NHS Lothian Staff Member

"It has filled a huge gap in supporting our patients. I wish I was able to refer more people to Sharlene."

- NHS Lothian Staff Member

"It is so much easier for us to get through to and provide the service we need to with her knowledge of the patients and their background experiences...enable us to provide the best care for the younger patients."

- NHS Lothian Staff Member

"Sharlene's time spent with the young adults allows us as a unit to provide more holistic care and promotes active patient engagement and compliance."

- NHS Lothian Staff Member

"The renal Young Adult Support Worker role has been a critical addition to the renal unit."

- NHS Lothian Staff Member

Coming soon: Art therapy project

A group of eight young adult renal patients collaborated with local Edinburgh artist, Fiona, for an eight week series of workshops at the Edinburgh Printmakers studio. The participants gained new artistic skills and used tools to create their own works of art, which were showcased at an opening event which was attended by 60 patients, their families and healthcare professionals. The collection, the patients decided will be called 'My Journey', will be publicly exhibited at the OPD 4, Tonic Arts Gallery in the Royal Infirmary Edinburgh from October 2025 to April 2026.

Next steps

Staff from the Renal Service unanimously agreed her role filled a critical gap in holistic care, with strong support for making the position permanent, which the Renal Medicine Clinical Management Team are exploring.

Thank you

Thank you to the young adults for sharing their experiences and to the staff in the Renal Service. Thank you to Sharlene for her support with this Impact Report. More information about Sharlene's role can be found [online](#). Information about how NHS Lothian Charity can support projects like this can be found on [their website](#).



Art therapy group

Report compiled by Rebecca Caulfield, Evaluation Manager, NHS Lothian Charity