



ANNUAL REVIEW

2020/2021



"I've seen families broken in this year of extreme pain during the pandemic. Families need someone that will hear them and offer the practical and emotional support they need .

We were lucky, we got that help from Kindred."

a Kindred parent, 2021

Kindred is a charity that supports families of children with complex needs. Our secret ingredient is that most of our staff and trustees are themselves parents of children with disabilities.

Nothing compares with finding out that your child has a medical condition or disability. At Kindred, we know from our experience what it is like for parents who feel isolated and bewildered. We want parents to feel that they are not alone and that we can help them to meet their child's needs. We provide information about benefits and schooling and support families through the process of diagnosis and medical treatment. But we find that the most important part of our service is listening to parents and hearing their story. Our listening skills have never been more needed than over the last year as parents have struggled to cope with the impact of the Covid-19 pandemic.

"Thank you for checking in on us during Covid, this means so much and I couldn't have done the DLA without your help."

"During the pandemic, we had to move out of the house where we were staying. We then became homeless with nowhere to go."

Kindred advised they would support me to find somewhere suitable for my child's health."

Now, thanks to Kindred my family has got a roof over its head. They make me feel like I am not alone."

What Kindred has delivered to families:

Last year Kindred provided individual support to 702 families.

Our teams completed
307 DLA or PIP
(Disability Living Allowance or Personal Independence Payment) forms.

We raised
£249,198
in charitable trust funding for aids, adaptations, equipment and specialist toys.

Our Facebook page has over
3,000 followers
providing regular updates and information.

We supported
172 families
with rehousing or housing adaptations.

Please give generously to support our work

the wider picture:
what our teams
have been up to



Our team at the Royal Hospital for Children and Young People

Our Hospital Team helped 195 families of whom 30% had a child in Paediatric Intensive Care. Our three staff helped families with grant applications, benefits and practical support as well as offering a listening ear.

Supporting families in Fife

Our Fife Team supported 223 families, including a very high proportion of very young children with complex needs referred by the Community Nursing Team.

Support from the Community Team

Our Community Team supported 284 families with a wide range of needs. We have particular expertise in supporting parents to establish the right school placement for their child.

Counselling and Bereavement Support

We have provided 21 parents with counselling, and a further 11 families have been supported with bereavement care.

What else have we been up to this year?

Kindred adapted quickly to the unexpected changes the pandemic brought with staff working from home and parent support offered through online video platforms and the telephone.

We conducted a survey *Covid-19 and Families of Children with Complex Medical Needs* in August 2020 with 42 Scottish families, sharing recommendations with multiagency professionals in training events, and with government and other organisations.

Our Hospital Team moved from its original 1991 base at the old 'Sick Kids' in Sciennes to the heart of the new Royal Hospital for Children and Young People in Little France, Edinburgh.

We had our first online AGM and Carol Concert, and facilitated several professional and parent webinars.

Kindred campaigned for parent carers of children with complex needs to be prioritised to receive the Covid-19 vaccine, and for pupils with additional support needs to return to full schooling safely.

Ian Rankin, author, parent, one time user and longterm supporter of Kindred, joined Sophie Pilgrim in a Radio Scotland interview about parenting those with complex needs during the pandemic.

*"I heard that we are
in the same boat.
But it's not that.
We are in the same
storm, but not in the
same boat".*

Damian Barr, 2020



Kindred Advocacy

Covid-19 and Families of Children
with Complex Medical Needs



October 2020



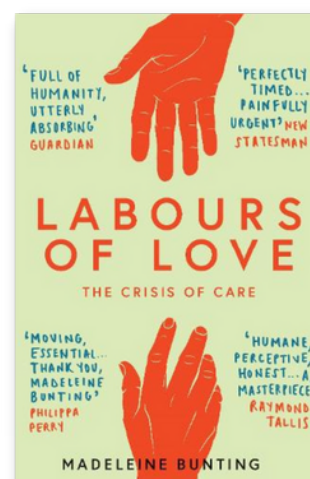
donate at www.justgiving.com/kindred

S supporting parent carers with their labours of love:

"I travelled north to the offices of a voluntary-sector organisation which offered support to families of children with a disability. Nothing prepared me for the intensity of the time I spent there.

I was to shadow appointments, visit families in their homes and interview staff for a few days. The cramped offices tucked into a basement on a side street of a busy city came to represent an electricity substation in my mind, but instead of routing power, it was handling emotions which could capsize lives and bureaucratic procedure.

Grief, anger, fear, shame, frustration: this was the raw stuff of the organisation's working day. Listening was their first task, then the hard slog over months, or even years, of helping families navigate their way through complex bureaucracies of health, education and social services to fight for the care of their child. The cases that arrived at the charity's door were the toughest: children who did not fit any straightforward diagnosis, parents overwhelmed by the interactions with professionals and the needs of their child. The charity was caught at the interface between desperate families and an overstretched system of services hit by budget cuts and intent on rationing care."



Madeleine Bunting describing her time observing Kindred's service,
Labours of Love: The Crisis of Care, Granta, 2020

"We want to say thank you very much for your help. If today, we are happy it is because you all have supported us. A big thank you from the bottom of our heart."

Rafaella, Anderson and Arthur



Offering a holistic service:

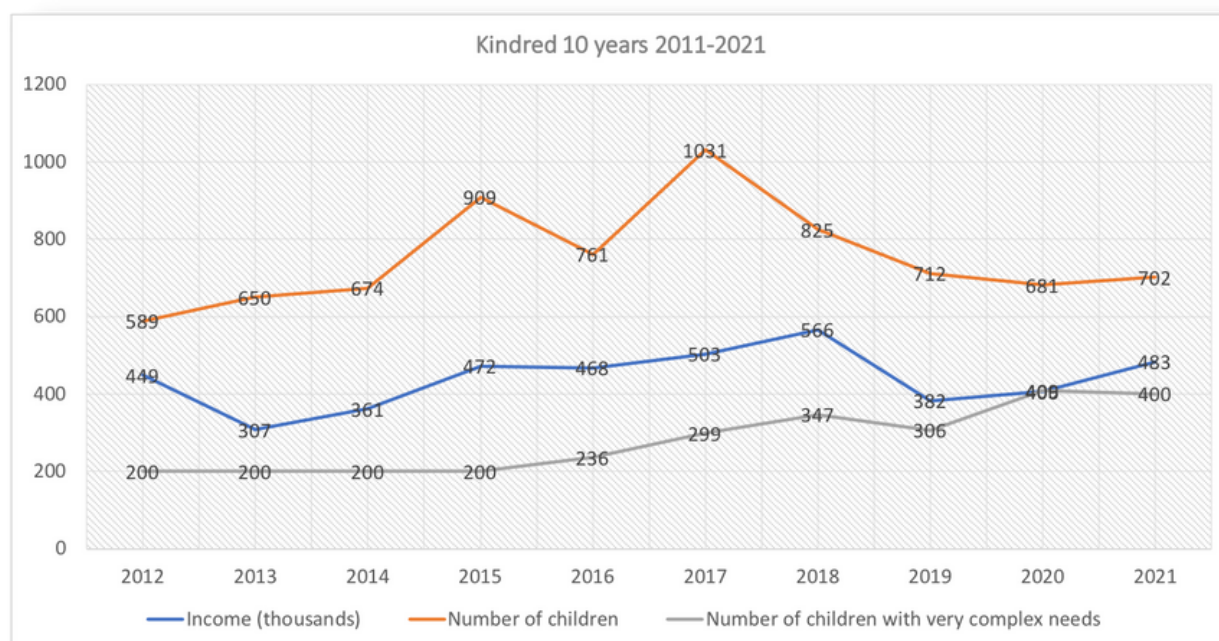
Kindred have such a breadth of knowledge and experience of working in hugely complex situations they are the most valuable resource.

I know if I have any general queries about complex scenarios I can knock on their door and get an answer. The parents that I know that are supported by Kindred only speak very highly of them and would be lost without them."

Gordon Linton, Discharge Liaison Nurse,
Royal Hospital for Children and Young People, Edinburgh

ten years and the changing picture of complex needs:

Over the last ten years Kindred has supported many thousands of families in Scotland. Four years ago, we took a strategic decision to support fewer families, and to focus our service on those with greatest need. This is reflected in our data which shows an increased proportion of children with very complex needs, but stability in the numbers of families which we support and in our income. In the last financial year we increased our reserves and maintained the same level of service, demonstrating resilience even in the face of the global pandemic. We are working to ensure that Kindred's service is sustainable.



Kindred are a wonderful charity who support families on their difficult journeys, providing emotional support and assisting with practicalities along the way.

I have been particularly impressed with the holistic support they provide and how they help support families in situations such as attending hospital for training, organising financial support and assisting with social issues.

They also work closely with our discharge planning nurse. It is really helpful for us as a medical team to know the family are being supported with the many additional factors in their life and that they are getting holistic support here at the hospital too."

Dr David Armstrong, Consultant Paediatrician

with special interest in Respiratory Medicine and High Dependency Care,
Royal Hospital for Children and Young People, Edinburgh

Our income: Kindred's income for the year ending 31 March 2021 was £483,099 and our expenditure was £401,966. In the current financial year we have increased our reserves to £113,811 while increasing our valued team from 12 to 13 permanent staff, with the recruitment of a fundraiser. This has enabled us to attract new funders and to develop our fundraising.

Kindred is funded by:

Scottish Government,
NHS Lothian,
Fife Health and Social Care,
National Lottery Community Fund,
The Cordis Trust,
The Henry Smith Foundation,
The Robertson Trust,
The R S MacDonald Charitable Trust,
The Agnes Hunter Trust,
Julia and Hans Rausing Trust,
The Bank of Scotland Foundation.

We are also grateful to:

Apple Tree Trust; Asda; Avenel Trust; Barratt Developments Plc; Charities Aid Foundation; Dentons; Edinburgh Police Choir; The Edward Gostling Foundation; Eldon Charitable Trust; James and Carole McGuire; Meikle Foundation; Morton Fraser LLP; PF Charitable Trust; The Sir James Thorn Charitable Trust; The Souter Charitable Trust; St James Scottish Episcopal Church; Stewart Investors; STV; The Murdoch Charitable Trust and Triangle Trust for their generous donations.

Special thanks to all those who have volunteered and/or raised funds for

Kindred including: The Taylor Family; Molly Paechter; Jenny Harris and Malcolm Cochrane.



**A few words from Claire Palmer,
Chair of Board of Trustees:**

"Since my twins were born Kindred have provided invaluable support to us in some of the most difficult situations any parents should have to endure. The charity is unique in the service it offers and as a family we feel very strongly connected to it."

It is therefore a privilege to be able to support Kindred by taking on the role of Chair".



Above left to right: Huma Barrie, Kindred outgoing Chair, with new Chair, Claire Palmer

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www.justgiving.com/kindred