There are at least 100,000* children and young people in the UK living with a serious illness or complex care needs. But sadly many of the families caring for these children and young people need more support than is often available.

Families caring for a child or young person with a serious illness or complex care needs can endure immense physical and emotional strain with the relentless 24-hour care routine and the continuous journeys to and from hospital. Whilst there are many excellent and committed doctors, nurses and professionals working in hospitals, at the community and in other settings, there isn’t enough support to go around.

Many families simply don’t have the help they need for their child.

Informed by the views of the families we support and the professionals we work with, WellChild’s Manifesto for Change presents a challenge to politicians and decision makers to ensure services improve for all families who are caring for children and young people with a serious illness or complex care needs, wherever they are and wherever they live in the UK.

* These are conservative estimates. Because of a lack of data, surprisingly little is known about the actual numbers of children and young people living with serious illness or complex care needs. This is something we want to change.

Our vision for children, young people and their families

Our vision is focused on the priority areas set out within this document. We are focussed on our vision to ensure better health outcomes for all UK children and young people with serious illnesses or complex care needs. We want these children, young people and their families to:

1. Receive the highest possible standard of care in hospital
2. Be fully supported in their journey from hospital to home
3. Have access to a full range of quality care and practical support services at home

WellChild believes that all children and young people should be cared for at home with their family wherever possible.

The priorities needed to improve the lives of children and young people living with serious illness or complex care needs, and their families

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WellChild is the national charity working to ensure the best possible care and support for all these children, young people and their families wherever they are and whenever they need it.

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Registered Office 1815689
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The priorities needed to improve the lives of children and young people living with serious illness or complex care needs, and their families

You would think that it should all fall into place in a planned and systematic way, but we find time and time again if you don’t shout and keep pestering, you don’t get it.

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The priorities needed to improve the lives of children and young people living with serious illness or complex care needs, and their families.
All children and young people living with a serious illness or complex care needs and their families should have the support they need to enable them to make the journey home from hospital as quickly and as efficiently as possible.

Children and young people can often spend month after month in hospital because there isn’t the support available for them to leave. Many parents say that they feel ill equipped to care for their child at home or that they feel daunted and scared by what it might be like without the support of hospital staff. Parents and carers of children and young people who have complex needs should have access to the full range of care and practical support they need when caring for their child at home.

To improve support for families at home, there needs to be:

- Equitable access to a children’s community nurse or WellChild Children’s Nurse who can provide ongoing care and support in the home and as and when needed.
- Practical help – including access to one named key worker – to enable families to navigate and access the range of support that local health, social services and other organisations can provide.
- Support for families such as access to short breaks and psychosocial care to enable them to cope, preventing readmission and allowing the child or young person and their brothers and sisters to have a childhood.

Being in hospital with a child who has complex needs is like being stuck in Groundhog Day. I find myself repeating her history, needs, medications and current problems over and over again. I just wish that the value of our children’s community nursing service could be recognised in terms of keeping families together and taking some of the strain off marriages and relationships.

To improve the situation, we are calling on policy makers to ensure that there is:

- Access to high quality nursing support and medical care in hospitals for children and young people.
- Better information for children, young people and their families at the point of admission to hospital – with a dedicated key worker to manage the process.
- More information, training and support to ensure parents and carers are competent and confident to care for their child or young person at home.
- Practical advocacy support in the hospital from one named key worker – someone who works with parents and professionals to ensure a clear, effective and individualised plan in place.

Better information for children, young people and their families.

Support for families when their child is in hospital – including emotional (eg psychological) and physical (eg access to somewhere to sleep).

Care and support in hospital can be rather hit and miss. Nurses are brilliant and mostly extremely conscientious and caring, but are also horribly overstretched and under-staffed, and the patients end up suffering. I find myself repeating her history, being stuck in Groundhog Day.

Being in hospital with a child who has complex needs is like being stuck in Groundhog Day. I find myself repeating her history, needs, medications and current problems over and over again.

The quality of care and support for these children and young people varies greatly from hospital to hospital. Parents say that often information is lacking and that there is inadequate access to basic support to enable them to care for both their child and themselves in a hospital environment.

To improve the situation, we are calling on policy makers to ensure that there is:

- Support to enable them to care for both their child and themselves in a hospital environment.
- Information for children, young people and their families at the point of admission to hospital – with a dedicated key worker to manage the process.
- More information, training and support to ensure parents and carers are competent and confident to care for their child or young person at home.
MANIFESTO PRIORITIES

1 All children and young people living with a serious illness or complex care needs and their families should receive the highest standard of care possible whether this is at a tertiary centre, on a specialist unit or in a district hospital.

2 All children and young people living with a serious illness or complex care needs and their families should have the support they need to enable them to make the journey home from hospital as quickly and as efficiently as possible.

3 Parents and carers of children and young people with a serious illness or complex care needs should have access to the full range of care and practical support they need when caring for their child at home.

To improve the situation, we are calling on policy makers to ensure that there is:

- Access to high quality nursing support and medical care in hospitals for children and young people.
- Better information for children, young people and their families at the point of admission to hospital as well as support for parents when their child or young person is a readmitted either planned or emergency.
- Support for families when their child is in hospital - including emotional (eg psychological) and physical (eg access to somewhere to sleep).
- Better access to developmentally appropriate hospital based services that recognise and support the individual needs of these children, young people and their families.
- More information, training and support to ensure parents and carers are competent and confident to care for their child or young person at home.
- Practical advocacy support in the hospital from one named key worker – someone who works with parents and professionals to ensure a clear, effective and individualised plan is in place.
- A fully integrated approach to the planning of care for children and young people in their homes.
- Monitoring tools in place to ensure support for children, young people and parents in the home addresses their individual needs.
- Equitable access to a children’s community nurse or WellChild Children’s Nurse who can provide ongoing care and support in the home as and when needed.
- Practical help – including access to one named key worker to enable families to navigate and access the range of support that local NHS, social services and other organisations can provide.
- Support for families (such as access to short breaks and psychological care) to enable them to cope, preventing readmission and allowing the child or young person and their brothers and sisters to have a childhood.

To improve support for families at home, there needs to be:

- Effective and seamless discharge process – which begins at the point of admission to hospital - with a dedicated key worker to manage the process.
- A better understanding of the obstacles, barriers and challenges parents face leading up to the point of discharge from hospital.
- Equitable access to a children’s community nurse or WellChild Children’s Nurse who can address their individual needs.
- Better integration across health, social care and education so it’s far easier for families to navigate through the maze of services.
- Commissioning models which are focussed on addressing children, young people and families’ needs at both national and local levels.
- Better support for families making the transition between different services at different ages including neonatal to children’s services and the move into adult services.
- Monitoring and reviewing so that the impact of such care can be measured and learning shared.

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2

All children and young people living with a serious illness or complex care needs and their families should have the support they need to enable them to make the journey home from hospital as quickly and as safely as possible.

We want children and young people to be cared for at home with their family around them wherever possible, and to achieve this priority, there needs to be:

- More information, training and support to ensure parents and carers are competent and confident to care for their child or young person at home.
- Practical advocacy support in the hospital from one named key worker – someone who works with parents and professionals to ensure a clear, effective and individualised plan is in place.
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- Monitoring tools in place to ensure support for children, young people and parents in the home addresses their individual needs.
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Monitoring tools in place to ensure support for children, young people and parents in the home can provide ongoing care and support in the home as and when needed.

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Monitoring tools in place to ensure support for children, young people and parents in the home can provide ongoing care and support in the home as and when needed.

3

Parents and carers of children and young people with a serious illness or complex care needs should have access to the full range of care and practical support they need when caring for their child at home.

Time and time again parents tell us about the lack of support that’s available to them in the community. They struggle with the burden of juggling all the professionals involved in their child’s care and find navigating the complicated health, education and social care systems a challenge.

Parents and carers of children and young people with a serious illness or complex care needs should have access to the full range of care and practical support they need when caring for their child at home.

All children and young people living with a serious illness or complex care needs and their families should have the support they need to enable them to make the journey home from hospital as quickly and as safely as possible.

More information, training and support to ensure parents and carers are competent and confident to care for their child or young person at home.

- An effective and seamless discharge process – which begins at the point of admission to hospital – with a dedicated key worker to manage the process.
- A fully integrated approach to the planning of care for children and young people in their homes.
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It’s vital to have access to the full range of care and practical support they need when caring for their child at home.

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MANIFESTO FOR CHANGE

There are at least 100,000* children and young people in the UK living with a serious illness or complex care needs. But sadly many of the families caring for these children and young people need more support than is often available.

Families caring for a child or young person with a serious illness or complex care needs are under immense physical and emotional strain with the relentless 24-hour care routine and the continuous journeys to and from hospital.

Whilst there are many excellent and committed doctors, nurses and professionals working in hospitals, in the community and in other settings, there isn’t enough support to go around.

Many families simply don’t have the help they need for their child.

Inspired by the views of the families we support and the professionals we work with, WellChild’s Manifesto for Change presents a challenge to politicians and decision makers to ensure services improve for all families who are caring for children and young people with a serious illness or complex care needs, wherever they are and wherever they live in the UK.

Our vision for children, young people and their families

The priority areas set out within this document are focused on our vision to ensure better health outcomes for all UK children and young people with serious illnesses or complex care needs.

We want these children, young people and their families to:

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About WellChild

There are thousands of children and young people in the UK living with a serious illness or complex care needs. WellChild is the national charity working to ensure the best possible care and support for all these children, young people and their families wherever they are and whenever they need it.

- Our network of WellChild Children’s Nurses provide practical and emotional support to children and young people with a serious illness or complex care needs and their families, enabling them to leave hospital and be cared for at home whenever possible.
- With the support of teams of volunteers, we make family homes and gardens a better, safer place for children and young people to learn, play and have fun.
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- We’ve invested more than £20 million in groundbreaking projects and research over the past 30 years leading to many improvements in children’s health spanning from pain relief to liver disease.
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The priorities needed to improve the lives of children and young people living with serious illness or complex care needs, and their families

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RECEIVE THE HIGHEST POSSIBLE STANDARD OF CARE IN HOSPITAL

BE FULLY SUPPORTED IN THEIR JOURNEY FROM HOSPITAL TO HOME

HAVE ACCESS TO A FULL RANGE OF QUALITY CARE AND PRACTICAL SUPPORT SERVICES AT HOME

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