

Children's Health Scotland



Welcome to our new Chief Executive

Te are delighted to welcome Helen Forrest as our new Chief Executive. Helen has now assumed responsibility for leading the dedicated staff team at Children's Health Scotland so that we can continue to raise our profile through direct support and advice, influencing policy and campaigning for service improvement.

Commenting on the appointment Richard Olver, Chair of Children's Health Scotland said: "I am delighted to welcome Helen as our new Chief Executive. Applications were received from a very high calibre of candidates and I am pleased it has concluded successfully with this appointment. I am now very much looking forward to working with Helen to take our charity forward – delivering on our strategic priorities so that we can continue to



further our mission for children and young people in Scotland."

Helen has over 25 years of senior experience within the voluntary sector in Scotland, working mainly

within the childcare sector and a demonstrable track record in strategy development, health improvement, engaging young people, and the transition from children to adult services. She said: "I am really excited to join the team at Children's Health Scotland. Together with the Board, I will now lead the continued development of the charity so that every child and young person can exercise their rights to healthcare and have these rights upheld and their healthcare needs met.

"With a working knowledge of the childcare and healthcare sectors, I am passionate about making a difference to the lives of children. In partnership with parents, carers and professionals I now hope to explore new ways to achieve this, directly through our own services at Children's Health Scotland and by working in partnership with others in the future."

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KT Tunstall announced as our new Patron

e are very proud to welcome awardwinning singer and songwriter KT Tunstall as our new Patron.

As Patron, KT will support the work of Children's Health Scotland whilst helping to raise the profile of the Scottish based charity and its mission, which is to enable every child and young person to exercise their rights to healthcare and to have these rights upheld, and their healthcare needs met, in partnership with their parents, carers and professionals.

KT Tunstall said: "I was adopted as a child and my brother Daniel is deaf, so I have total admiration and an affiliation with the work of Children's Health Scotland. I know the importance of the services they provide and also the many challenges they face.

"I am extremely impressed at the way they work with children and young people to support their mental health and reduce the anxiety they may face with any medical or dental treatment or being admitted to hospital. Many of these children are looked after or have additional support needs associated with long-term medical conditions, which is why I'm right behind their national work.

"I'm so excited to support Children's Health Scotland, bringing the benefits of my experience and my international profile to this role so that the charity can successfully continue to provide support to vulnerable children and young people. I am honoured to become their Patron."

Commenting on the announcement Professor Richard Olver, Chair of Children's Health Scotland said: "We can only continue to exist and provide our services in the community because of the support of donors and volunteers. It's great to have the support of an award-winning singer and songwriter like KT, and on behalf of everyone who works for Children's Health Scotland and the children, young people and families who use our services, I would like to say a huge thank you for her support and patronage. I know that she will be a fantastic Patron for our charity, and we look forward to a long and productive working relationship."

Children's Health Scotland is the only national charity that works to promote the healthcare needs and rights of children and young people. We are the national voice for children's health, championing their healthcare needs and working to ensure they are met throughout



I have total admiration and an affiliation with the work of Children's Health Scotland.

KT Tunstall, Patron, Children's Health Scotland

Scotland. We support children and young people, some with a range of mental health or chronic conditions, to develop skills and strategies to self-manage their conditions. We also focus on the healthcare needs of looked after children and young people and those who are 'hard to reach', ensuring they are represented.



Report on children and young people's mental health echoes young people's voices

he Scottish Parliament's Public Audit and Post-legislative Scrutiny Committee has released its report on children and young people's mental health. The recommendations echo what children and young people themselves have said.

Last year, the Children & Young People's Commissioner Scotland supported young people from Scotland to be among those who produced a series of recommendations about how countries across Europe could get better at realising children and young people's right to the best mental health possible. The European Network of Young Advisers (ENYA) created 48 recommendations in total. One of these chimes with a key conclusion of the Committee, that more research is needed around children and young people's mental health in general.

And several other of the Committee's recommendations focus on ways in which things should change across education, health, media, government and the wider community so that young people have access to the support that they need.



To read the full report, copy and paste the following link into your browser: https://digitalpublications.parliament.scot/Committees/Report/PAPLS/2019/3/14/Report-on-children-and-young-people-s-mental-health

World class hospital to open in July

e're very excited that the opening of the state-of the-art £150 million Royal Hospital for Children and Young People and Department of Clinical Neurosciences is now on the horizon.

From 9 July, the Children's Emergency Department (ED) will transfer to the new hospital next to the Royal Infirmary of Edinburgh at Little France. The world class facility will also open its doors to new patients on that date. Jim Crombie, Deputy Chief Executive

of NHS Lothian, said a new chapter was beginning following a 150-year glittering history of the Royal Hospital of Sick Children, which has provided care to millions of children across Edinburgh, Lothian and beyond. He added:

"This is such an exciting time to be part of NHS Lothian's children and young people's services. It is the beginning of a new chapter and we can't wait to move into our new home. It has taken a huge amount of commitment, dedication and sheer hard work to get to this point. Staff, patients and their families and friends

have all contributed to imagining and creating this world-class hospital."

"It is a huge project and a major operation is underway to ensure everything runs as smoothly as possible. Many of us – staff, patients and families alike have a real affection for the old Royal Hospital for Sick Children at Sciennes so I don't doubt there will be the odd tear shed when it closes its doors for the last time. However, we are confident that this magnificent new building and its wonderful staff will be just as important and cherished in the lives of families in the years to come."



My Jour

Cameron Elliot, Youth Volunteer

y name is Cameron. I am 17 years old and have hydrocephalus. Because of my condition, there is too much fluid in my head. This is controlled by a machine that takes some fluid away.

Before attending the Self Management Project with Children's Health Scotland (CHS), I was very selfconscious about my condition and could be nervous in public such as in school or at other times when I found myself around a lot of people. Even short time frames such as public transport could be scary. Because of all this, my confidence was quite low and I struggled to socialize and make friends which hurt me as I was quite lonely a lot of the time.

When I was 15 however, I was told about about CHS which supported young people with long term conditions and I could not have known, until I participated in their workshops, how fully they delivered on that one main aim. They allowed me to express myself in a safe environment surrounded by understanding, similar people and I could not have been more grateful and relieved because of this. I felt I could finally be in social situations and still be able to stay calm. My confidence increased so much too.

I could tell very quickly I was going to enjoy being with other people and feel far more comfortable. The coping strategies for scary times too were invaluable. I loved too, how we covered a new topic each week which was so important and productive in improving our mental health.

At the end of the workshop I was

given a big leaflet summarising all the lessons we had while there, as a reminder and reassured by the leaders we could receive support any time we required or just wanted it. This too was a huge comfort as we knew we would not be losing the people who had helped us so much over the time we were all there.

Anyone with a long-term condition should participate, I think, as it teaches you life skills. You are taught to control yourself during hard times and become far more independent in this way too. You are able to manage yourself far better, and again are far less reliant on others to help you, therefore you can cope whether you have lots of people around you or if it is just yourself. Because all areas are covered by the leaders, you have so many different coping methods to turn to, which is so crucial as you can always apply this to lots of separate scenarios where a person may find themselves uncertain.

Simply, CHS and the the workshops provided a supporting network and good experience. They were a massive help overall. After my brilliant experience taking part in the workshops, I felt I would be interested in contributing to the



fantastic support services of CHS and decided to join as a Youth Volunteer. This way, I knew I could help the organisation in their key objectives and also gain good experience in a workplace environment. I have taken on a number of different tasks that will aid me in the future work as well. For example as a Youth Volunteer, I am able to give a young person's perspective on activities, literature and CHS campaigns. It has also allowed me to give back Peer Support to other young people attending the workshops and I get to be involved in some of the preparation work for this! I would recommend volunteering at CHS as you can help lots of children and young people and improve yourself at the same time.



Safeguarding

he Scottish Government is seeking views on how best to incorporate the UN's 'gold standard' for children's rights into Scots law and improve the lives of children and young people.

The United Nations Convention on the Rights of the Child (UNCRC) is the most complete statement of children's rights ever produced and sets out the rights of every child, irrespective of where they live, the religion they follow or the make-up of their society. This includes rights to be treated fairly and equally, the right to be as healthy as possible, and the right to be heard.

Full and direct incorporation of the UNCRC will mean that those in power can be held to account to ensure children have what they need to thrive.

Incorporating the UNCRC will strengthen existing work to protect and respect children, and the consultation seeks views on the best way to do this within the context of Scots law, and the powers of the Scottish Parliament.

Deputy First Minister John Swinney said: "The UNCRC is recognised internationally as the 'gold standard', and we believe it is time to incorporate the UNCRC into domestic law. This will ensure that children's rights are woven into policy, law and decision-making. Children will be empowered to know and understand their rights and, if necessary, defend them in court. This will improve outcomes for

children and young people and help make Scotland the best place in the world to grow up."

Commenting on the consultation, Professor Richard Olver, Chair of Children's Health Scotland said: "We warmly welcome the launch of the Scottish Government's consultation on the incorporation of the UN Convention on the Rights of the Child into Scottish law. Promoting the healthcare rights and needs of children and young people lies at the heart of what Children's Health Scotland stands for and we agree with the Scottish Government that incorporation of the UNCRC has the potential to transform the experience of children, young people and their families across Scotland. However, it is one thing to have it woven into policy, quite another to give it effect in decision making and action, which are key to making a difference to children's lives."

Bruce Adamson, Children and Young People's Commissioner, said that incorporating the United Nations Convention on the Rights of the Child is the most important thing that Scotland can do to protect children's human rights. He said: "Full and direct incorporation of the UNCRC will mean that those in power can be held to account to ensure children have what they need to thrive, including good quality healthcare, housing, education, nutritious food and a clean environment.

"The Government has committed to make this a reality for children in Scotland in this parliamentary session and by November 2019, the 30th anniversary of the UNCRC, the Scottish Government's own proposed Bill must be before the Parliament to ensure that happens."





"It is vital that this consultation quickly results in tangible and concrete changes to Scots law to fully incorporate the UNCRC in its entirety and ensure that children's human rights are realised in Scotland."

Children's rights are human rights and apply to everyone under the age of 18. Children's rights set out within the UNCRC include the right to:

- · Life, survival and development
- Protection from violence, abuse or neglect
- An education that enables children to fulfil their potential
- Be raised by, or have a relationship with, their parents
- · Express their opinions and be listened to

A guide for children and young people to the UNCRC can be can be viewed on the Scottish Government website - www.gov.scot

The Programme for Government 2018-2019 committed the Scottish Government to consulting on incorporating the principles of the UNCRC into domestic law. Incorporating the UN Convention on the Rights of the Child into Scots Law Consultation can be viewed at https://consult.gov.scot/children-and-families/uncrc/

The consultation runs until 14 August 2019. Following consultation, the Scottish Government intends to deliver legislation in this parliamentary session.

Children's Health Scotland plans to submit a response to this consultation and we are keen to hear the views from our sector. If you would like to be included, please feed in your responses to Helen Forrest, Chief Executive of Children's Health Scotland by 14 July 2019, email h.forrest@childrenshealthscotland.org.

This will improve outcomes for children and young people and help make Scotland the best place in the world to grow up.

CHILDREN 8
YOUNG PEOPLE'S
Commissioner
Scotland







Scotland



Lisa's story

Lisa's story shows how she, as a young disabled person, exercised the rights described in the Rights **Awareness section of the Supporting** Disabled Children, Young People and their Families Guidance to make a big life decision - something that's had a really positive impact on her life.

This story first appeared on the Fairer Scotland blog. To read Lisa's story online visit

https://blogs.gov.scot/fairerscotland/2019/05/03/lisas-story/

Lisa explains why it is important to understand what is going on and to be involved in decisions about her care.

She understands:

Young people have the right to information in a way they can understand.

EACH Charter point 4





Hi, my name is Lisa.

I have a rare and complicated condition where my brain is malformed and causes severe seizures and a learning difficulty. I also have a facial disfigurement and have had many complicated and big operations. One time, when we were planning another very big and complicated operation to my jaw and face, my mum said to me:

"You trust me, don't you?" and I said: "Of course, you are my mum!" Then she said: "Do you trust Mr R?" (Mr R is my surgeon). I answered: "Yes, I do. He has known me all my life and I like him". After that my mum asked me: "Your next operation is going to be really big and complicated. It might all be a bit difficult for you to understand. Why don't I discuss it with Mr R and he and I can decide what the best way forward is for you?"

I was horrified. All I could say was: "But it is my face!" I know that my mum and Mr R always think of what's best for me, but I really didn't like for them to make decisions about me and my operations without me.

So, after that Mr R explained all the possible options to me and I talked it over with my mum and dad many times. I also spoke to a psychologist about it.

I think they all wanted to make sure that I didn't have the wrong ideas or expected too much. They also wanted me know that there might be risks and that it might not turn out the way I hoped.

When I finally had the operation, I was 14 years old. Mr R gave me a sheet before the operation and said: "You understand everything that's going to happen, therefore I think you could sign this consent form yourself."

I had to ask him what "consent" meant. He explained that it meant I gave him permission to do this operation and that I fully understood what he was going to do and what could go wrong.

It made me feel very grown up and I felt that I had made my own decision about my health and my face. I was very proud of how I coped with it all.



Young people should be listened to and take part in all decisions affecting their health care.

EACH Charter point 5









hildren's Health Scotland is proud to be one of the organisations involved in the consultation process and development of this important guidance that was launched by the Scottish Government on 24 April 2019. The aim of the guidance is to help improve the experiences of disabled children, young people, and their families and it was developed because families said they would favour a centralised resource which signposts to relevant information and organisations.

Its vision is: "To provide clear, accessible information on national policies, entitlements, rights and the different options for support available. We have used real life stories of children and young people which can highlight how support or a service available in their area helped them."

Commenting on the launch of the guidance Dagmar Kerr, Area Coordinator for Greater Glasgow and Clyde with Children's Health Scotland said: "We are pleased with the final result and this comprehensive online resource will grow and change with the comments that readers are encouraged to leave at the end of each page.

"To support its development we scrutinised the draft document with particular regard to how the healthcare rights of disabled children and young people were being met. Being guided by the ten articles which describe children's healthcare rights in the EACH Charter, we linked them to the principles of the UNCRC and GIRFEC to construct our comments. In the process

we suggested a number of health and rights related links and followed our key principle that every child and young person has these rights – regardless of any condition or disability.

"We also supplied some case studies to enhance the importance of meeting children's and young people's rights. In our magazine is Lisa's story, which describes why it is important to listen to them and to involve them in decisions about their health.

"Lisa and other children and young people and their families who provided "stories" for the resource, as well as representatives from organisations who submitted comments on the draft, attended the launch of the guidance in Edinburgh. There they met with Maree Todd MSP, Minister for Children and young people and had an opportunity to chat with her about matters important to them."

Our vision for this resource:

"We aim to provide clear, accessible information on national policies, entitlements, rights and the different options for support available. We have used real life stories of children and young people which can highlight how support or a service available in their area helped them."

To view this resource visit:

https://www.gov.scot/publications/supporting-disabled-children-young-people-and-their-families/





Keeping children hydrated before their operations

Dr Alyson Walker, Consultant Paediatric Anaesthetist and Lead of the Fasting Improvement Team

he Fasting Improvement Team (FIT) at the Royal Hospital for Children in Glasgow has been working hard to tackle overfasting of children before their procedures. Children must fast before anaesthesia to decrease the risk of aspiration (food or fluid going into the lungs). The food fasting time is 6 hours, and for clear fluids (i.e. diluting juice and water) is 1 hour.

When children are fasted for too long, they have a higher risk of nausea, low blood sugars and difficult cannulation, not to mention being more irritable and less satisfied. This can be a particular problem if a child is coming in for an afternoon operation and has not had breakfast that morning.

To tackle these problems, the FIT have introduced several changes, including:

 Introducing a 'I Can Drink Until' Card as a prompt to communicate a time they can safely drink until.

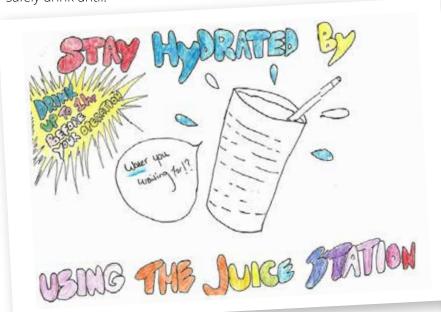
- Introducing a hydration station where parents can help themselves to diluting juice for their children.
- Re-writing the guidance on breakfast times to be at 7.30am (instead of the previous 6.45am).
- Redesigning the pre-operative information leaflets to be clearer for parents and patients.
- Running a poster competition for the children to design a poster to promote hydration before their surgery.



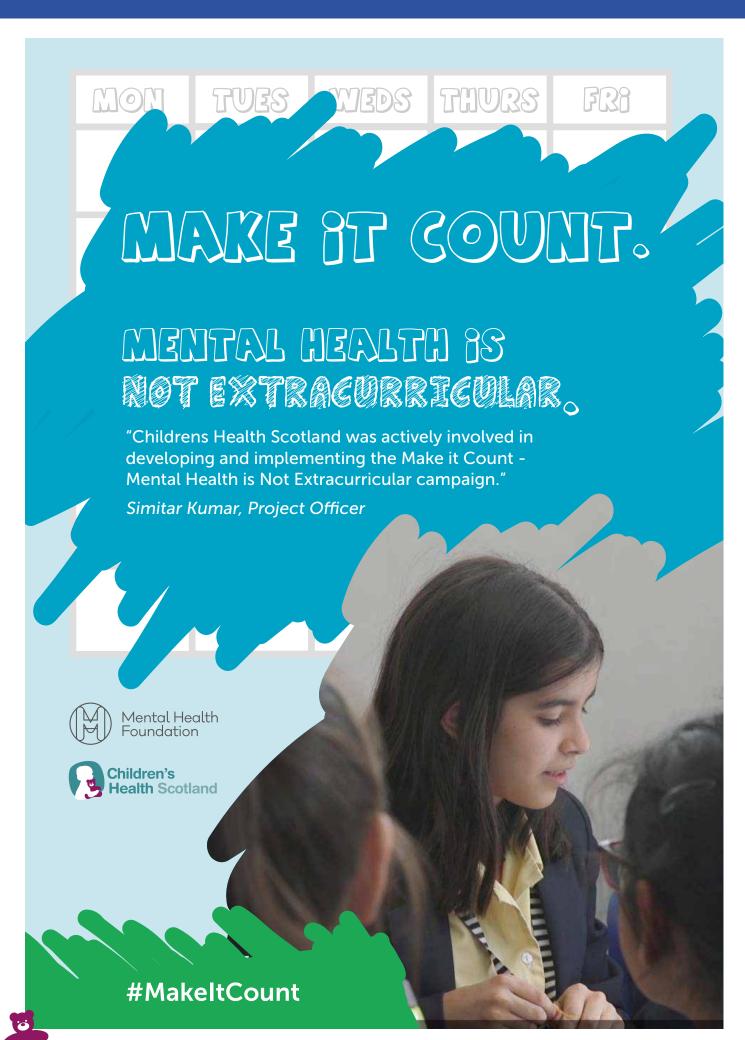
 The purchase of a new freezer so that children can be offered ice lollies up until an hour before their procedures.

These changes have gone a long way to improve not only the fasting times and compliance with having breakfast, but also improving patient and parent satisfaction. We are working on introducing a text-reminder service for patients coming in for procedures, so watch this space!

If you have any suggestions for how your child's experience could be better when coming in for an operation, then please contact alyson.walker@ggc.scot.nhs.uk with your ideas.







Body image and Mental Health Awareness Week

■his year Children's Health Scotland welcomed the theme of Mental Health Awareness Week, which ran in May 2019. Spearheaded by the Mental Health Foundation, the week concentrated on body image - how we think and feel about our bodies.

"Body image is such an important subject especially for children and young people in Scotland," said Helen Forrest, Chief Executive of Children's Health Scotland. "Body image worries can impact on self-esteem, confidence, health and wellbeing and

we therefore welcomed the focus of Mental Health Awareness Week 2019. with others in our sector to support children and young people and address head-on the pressures they face on a daily basis."

Our organisation will continue to work

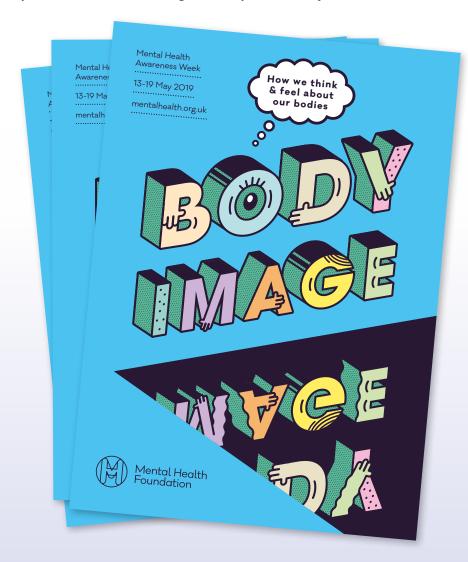
'Body image' is a term that can be used to describe how we think and feel about our bodies. Our thoughts and feelings about our bodies can impact us throughout our lives, affecting, more generally, the way we feel about ourselves and our mental health and wellbeing.

One Mental Health project that Children's Health Scotland was actively involved in developing and implementing was the Make It Count - Mental Health is Not Extracurricular Campaign.

This project aims to prevent mental health problems arising in adulthood by supporting young people earlier. More and more children and young people are struggling to cope with their mental health amidst rising rates of depression, anxiety and self-harm.

Commenting on the project Simita Kumar, Project Officer said: "Our organisation exists to ensure the healthcare needs of children and young people are met and long term conditions like arthritis, spina bifida, epilepsy and diabetes can have a profound impact on their mental health.

"Young people with these conditions often become real experts in what they need physically by getting to know their bodies, but often we don't help them to think about what they need to stay mentally well. If children can be supported to self-manage their mental health as well as their physical health, we can prevent poor mental wellbeing in childhood and the emergence of mental health problems into adulthood."



For more on the Make it Count project visit:

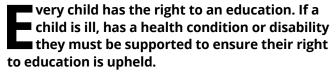
www.mentalhealth.org.uk/campaigns/mental-health-schools-make-it-count.





Healthcare in Schools

UNCRC Article 28 (right to education) EACH Article 7



"Children want and need adults in school to understand their needs and be there for them to support learning and engagement in the full life of the school, as and when they need it. This is partly about an adult commitment to seeing learning and school from the child's viewpoint, but also a matter of appropriate resourcing, particularly for children with additional support for learning needs." 'What Kind of Scotland?' (Children's Parliament, Page 19.)

Children and young people experiencing health challenges are entitled to additional support to achieve the same educational rights as their peers. The Scottish Education Acts of 1980 and 2000 set out the right to "adequate and efficient education" that develops the child "to their fullest potential." However, some children and young people are not getting the support they need.

A recent Additional Support Needs tribunal, illustrated the case of a child with Type 1 diabetes, who said he was not getting the support he needed to administer insulin at school. Some children and young people have had extended periods of absence because appropriate healthcare has not been made available in school, suggesting deficiencies in staff training and/or resources. A lack of appropriate support not only impacts on the child's right to health (Article 24), but also on their rights to education (Article 28), non-discrimination (Article 2) and the rights of children with disabilities (Article 23). Periods of absence can also contribute to feelings of isolation and lower self-esteem.

Children and young people with health conditions may meet the criteria for being legally considered as disabled (under the Equality Act 2010) and may be recognised



as having additional support for learning needs (under the Additional Support for Learning (Scotland) Act 2004). As such they may be eligible for additional planning, support and protective measures in their education. The Scottish Government produced guidance in 2015 and 2017 on children's education in the context of ill health. The Children and Young People (Scotland) Act 2014, places a duty on Ministers and public bodies to consider the UNCRC and individual-based planning and provision measures set out under the Scottish Government's Getting it right for every child (GIRFEC).

Despite the strength of existing legislation, there appears to be a gap between legislation and practice. There is evidence nationally of falling numbers of qualified learning support and other specialist teachers and of classroom and school assistants. These staff work with primary and secondary teachers in supporting pupils with additional support needs of all kinds, including those that are health-related and who may require healthcare in school. Statistics highlight that, while the number of pupils with additional support needs more than doubled between 2010-2016 (from 69,587 to 170,329), the number of additional support for learning teachers decreased by 15% in the same period (from 3,518 to 2,990).

Incorporation of the UNCRC into Scots Law would be key to closing this gap between legislation and practice. The promotion and development of a human rights culture in all institutions working with and for children and young people is vital to ensuring that all staff understand their duties towards children and young people and uphold these. Incorporation helps ensure the translation of rights into practice, through the promotion of child-rights training, participatory-led approaches, child rights-based budgeting and accountability mechanisms.

This story first appeared as a Together Scotland Blog. To view online visit

https://togetherscotland.blog/2019/05/27/healthcare-in-schools/







Proud to support **Foster Care Fortnight**

ostering has the potential to be life-changing for fostered children and young people. It can #changeafuture and Children's Health Scotland was proud once again to support Foster Care Fortnight 2019.

"We absolutely believe that foster care changes futures," said Helen Forrest, Chief Executive of Children's Health Scotland. "It changes both the futures of fostered children and young people and the futures of the foster families who care for them, and I am really proud that our fostering healthcare programme that we deliver, firmly focuses on how children and young people can be supported at these times of need."

Children's Health Scotland promotes the needs of all children and young people in the healthcare system, working for improved standards and quality of care whether they are ill in hospital, at home, or in the community. Included are children and young people in care who may not enjoy the love and support of a caring family. Recent Scottish Government policy has focused on the needs of this group, as there has been considerable concern at the less than favourable outcomes for children and young people who are looked after, whether at home or away from home either in foster, kinship or residential care.



Commenting on Foster Care Fortnight, Anne Wilson, Development Officer at Children's Health Scotland said: "To help carers gain a deeper understanding of the healthcare needs and rights of children and young people who are in or leaving care, Children's Health Scotland developed training that has helped to change futures. The main focus of this training is how children and young people's healthcare needs can best be supported and to enable access to appropriate healthcare services.

"During Foster Care Fortnight we highlighted that there are often additional complex healthcare issues for children in kinship care. For example, these issues can be around birth parents' mental health, fear of inherited conditions, challenges relating to consent and confidentiality and tensions relating to a child coming into care in the first place. To help address these issues, we also run a Kinship Carer programme that ultimately focuses on supporting carers to manage the children's healthcare."

#changeafuture

The theme of this year's Foster Care Fortnight was how foster care changes futures - the futures of fostered children and young people and the lives of the foster families who care for them.



#myhealthmyrights

MY HEALTH: We offer information and resources and represent and support all children and young people and their families when they need help with their healthcare and the right to it.

MY MIND: We provide workshops for children and young people, some with a range of mental health and chronic conditions, to develop skills and strategies to self-manage their conditions.

MY VOICE: We give support and advice and promote and campaign so that the voices of children, young people and their families are heard throughout Scotland.

MY RIGHTS: We exist to raise awareness of children's health rights.



We care that ALL children and young people are fairly treated within our healthcare system. Do you?

Help us make sure young people get treated well. PLEASE DONATE TODAY

If you would like to make a donation to help fund our work with ALL sick children and young people in Scotland regardless of their illness or condition then please send a cheque to the address below or go online at www.childrenshealthscotland.org and click the donate button.

THANK YOU

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Find us on:









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