



# Action for Sick Children Scotland

Newsletter



Winter 2016/17

Action for Sick Children Scotland

Is the only charity in Scotland dedicated to informing, promoting and campaigning on behalf of the needs of ALL sick children within our healthcare system. Our work includes:

Working with the Scottish Government, NHS and voluntary sector to ensure that health services are planned for sick children and young people in child centred environments with appropriate ratios of trained staff

Informing children, parents and carers of their rights and responsibilities; empowering them to participate in decisions about treatment and care

Raising awareness, representing children's needs and concerns within government, healthcare committees and other non-governmental organisations

Promoting high quality of health care services at home and in hospital, while working to obtain equality of services and access across Scotland

## Tackling Childhood Obesity Intervention Programme in Tayside

As a nation, our adults and children are becoming heavier and it would be easy to see this heavier weight as the norm. More than 30% of children and young people in Scotland are currently classed as overweight or obese and this has a major implication for their future health.

The consequences of obesity in children and young people include heart disease, insulin resistance and type II diabetes, dyslipidaemia, high blood pressure, psychological and social morbidity, asthma, impaired fertility, orthopaedic issues, breathing problems and sleep apnoea, fatty liver disease, association with some cancers (more so than smoking) and persistence of obesity into adulthood. The management of such health conditions is likely to have a significant financial impact on the NHS and society given that childhood obesity can often last into later life. Children and young people can suffer emotionally as they may be bullied or lack confidence and self esteem. With this in mind, and in an aim to address an increase in the



At least one hour of physical activity a day is needed

number of overweight and obese children and young people, the Scottish Government introduced HEAT Targets in 2008 and this saw a requirement for all health boards to offer a Weight Management Programme. NHS Tayside introduced the Paediatric Overweight Service Tayside (POST), a Family-based Healthy Weight Intervention Programme. Our Area Officer in Tayside recently attended two training sessions delivered by POST - Introduction to Childhood Obesity Level 1 and Level 2 and learned more

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## E-learning Resource on Children and Young People in Care

ASCS's e-learning resource, 'Health Matters for Looked after Children', has two modules:

- 1) managing the healthcare needs and rights of children and young people in care and
- 2) mental health and emotional wellbeing.

These modules are designed to enhance the knowledge and understanding of professionals working with care experienced children. They were developed in conjunction with the University of Stirling and Learnpro and have now been sent to all health boards. They have been well-received and feedback includes:

*I was asked by my Manager to review them as to their suitability for general use in the NHS ... I was able to say I would thoroughly recommend them!*



*I really like the interactive nature of them and the content is easy to navigate. They are a fabulous resource and I'd be more than happy to request them for our Board.*

NHS staff with an interest in this area should contact the Learning and Development team in their local health board for more information.

Those outwith the NHS can contact Learnpro to request a preview on 0131 551 4666 [support@learnpro.co.uk](mailto:support@learnpro.co.uk) or [www.learnpro.co.uk](http://www.learnpro.co.uk)

Promoting the Healthcare Rights and Needs of Children and Young People



Continued from page 1 Tackling Childhood Obesity

about the Programme, which Action for Sick Children Scotland believes is an example of good practice.

Since children and young people are growing, BMI (body mass index) is not a static measurement and is different for boys and girls. BMI centile charts are used to plot each **child's BMI against population standards for their age group** and gender in order to identify those who are most overweight or obese. The Scottish Intercollegiate Guidelines Network (SIGN) identifies children at or above the 91<sup>st</sup> centile of the population as being overweight (ie in the top 9% of the age matched child population) and those at or above the 98<sup>th</sup> centile as being obese.

The POST programme uses a family-centred approach to support children up to 16 years and their families to adopt a healthy lifestyle and to take control of their own lifestyle changes. Practitioners ensure they establish a shared agenda and manage expectations between themselves and the child and their family. The behaviour change model and change tools are used to assist clients in raising their awareness of lifestyle, focus on the aspects of lifestyle which require change and develop strategies to implement and monitor these changes. The 2013 (National Institute for Clinical Excellence) NICE 43 and the 2010 SIGN 115 obesity guidelines suggested that these are essential techniques for use in behavioural intervention programmes with children.

Discussing weight can be a very sensitive matter, not only for the children and young people themselves, but also for parents. The programme has been designed with this in mind, for example all clinical sessions are held outside of NHS premises and in local community or leisure centres. Whilst practitioners speak the truth, are precise and do not couch the message, they always aim to show acceptance and **empathy referring to 'healthy weight' as opposed to obese** or overweight. Referrals for children and young people who have a BMI on the 91<sup>st</sup> centile or above are accepted from a variety of professionals as well as from parents and carers. The programmes include Individual Family and Group Family Programmes, as well as physical activity input through the Get Going groups across Tayside and are usually delivered over 3 – 5 months. The main aim is to support positive changes in family lifestyle – healthier diet, increased physical activity and decreased screen time. Most children and **young people who are in an unhealthy weight range won't** need to lose weight. As they grow taller, the aim is to maintain their weight by balancing energy in (cutting down on foods high in fat and sugar and limiting portion sizes) and energy out (participation in at least 1 hour of physical activity each day and reduced screen time). A traffic light system is used to introduce easy to follow healthy eating plans Red Foods – high in fat and sugar, Amber Foods – important for a healthy body, and Green Foods – packed full of vitamins and low in fat and sugar. For further information about POST Tayside visit their facebook page <http://www.facebook.com/nhstaysidePOST> and you can follow on twitter @POSTNHST

## Reaching Out to More Families



Our new Development Officer, Shona Agnew, took up post in July 2016 and has been targeting families that ASCS has found harder to reach. This includes families affected by any sort of barrier to getting their children access to health services and those who may not know about the support we can offer. In 2017 we hope to offer staff who support these families, parents/carers and young

**people, training on children's health rights. We also want to work with these families to try and improve their children's health care experiences. For more information or to make a referral, email Shona at:**

[s.agnew@ascscotland.org.uk](mailto:s.agnew@ascscotland.org.uk) or phone 0131 553 6553.

## ASCS Self Management Programme



*There is focus on learning coping skills, having fun and making friends*

Our Self-Management Project in Lothian has been busy since its start last August. We have engaged with over 30 children and young people in our workshops. An external evaluator also interviewed 19 children and young people, parents and clinicians over the summer. We are pleased to report that all children and young people interviewed reported increased self-confidence and communication skills and everyone interviewed would recommend the programme to others! Feedback has been fantastic.

**'I've gained more confidence around new people about talking about my condition. Usually I would not really say anything or do anything, but if I would come to the group now with some new people I would feel more confident to talk to them'**– Young Person.

**'Loved the fact he was with people that understood him and that he felt comfortable in the group...It's lifted a burden off my family, knowing he's confident, I'm not so anxious!'** - Parent.

**'We're having conversations, plus feedback from his carer who couldn't believe the difference in him, said his face lit up, he gave feedback, he laughed and was happy to be there'**– Clinician.

We are absolutely delighted that following this successful evaluation, The Sick Kids Friends Foundation has renewed funding for another year. To join our mailing list or to be informed about new workshop dates please contact Simita Kumar (Project Officer) [s.kumar@ascscotland.org.uk](mailto:s.kumar@ascscotland.org.uk)

## Children's Rights Guide Our Work in Greater Glasgow & Clyde

Dagmar Kerr, our Area Co-ordinator in the health board writes:

'In January 2017, it will be 25 years since the UNCRC came into force in the United Kingdom.

**UNCRC celebration planned**  
The Rights of the Child Group is using this date to celebrate children's rights within the healthcare system. These rights are of course clearly stated in the *EACH Charter* and on 17 January 2017, the Royal Hospital for Children Glasgow will host a day of activities, art and competition. The aim will be to raise awareness of the rights among young patients, their families and staff. The event will be supported by **ASCS and the hospital's Children's Charity. Hospital play staff and youth workers** are engaging with patients so that they can demonstrate why their rights are so important. Look out for more information about this on social media.

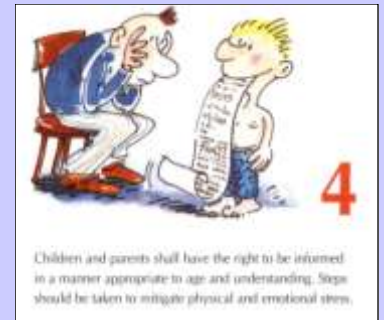
**Consultation on Ward 15 Royal Alexandra Hospital**  
The Health Board has started the consultation process about the **proposed move of the children's**

inpatient and short stay ward (Ward 15) at the Royal Alexandra Hospital **Paisley to the new children's hospital** in Glasgow. I am a member of the Stakeholder Reference Group and work closely with all members to ensure that **children's rights to the best possible healthcare** are at the centre of this process. Affected families are looking for reassurance that appropriate transport links will be available, that essential community services will remain in Paisley and that a move to the new hospital will indeed mean better access to better services. The Health Board is making every effort to make the process transparent and open. Staff from the engagement team are available to **answer questions and the board's website <http://www.nhsggc.org.uk>** gives detailed information of the process.

**Transition Policy and Pathway Planned**  
Work has stepped up in the health board to develop a robust transition policy so that young people with ongoing or chronic conditions will be able to follow a suitable pathway when they move from paediatric healthcare to adult services. This can

be a difficult time for young people and their families. At this time in their lives, young people may also be leaving school, becoming more independent and want to take control over their own healthcare. While there are some very good examples of transition for **certain conditions, there isn't yet a system that works for all condition and allows for person centred planning with paediatric and adult services working together (*EACH Charter 9, continuity of care*).** I am delighted **that I will be part of this work.'**

### Review of Conscious Sedation Guideline



The Scottish Dental Clinical Effectiveness Programme, (SDCEP) is currently revising the guideline on conscious sedation in dentistry.

Our Area Co-ordinator, Dagmar Kerr is contributing to this work as a **'lay representative'**. **ASCS strongly** believes that good and appropriate preparation, for example through play or with personalised story books, can help children and young people of all abilities to cope with dental procedures and might avoid the need for general anaesthetics or sedation. This has been clearly demonstrated during our successful Special Smiles Project. There has been a lot of effort to reflect this in the SDCEP guidance sections about consent and patient involvement.

*EACH Charter points 4 and 5 about information and involvement* were essential for this. To comment on the draft guideline, please visit: <http://www.sdcep.org.uk/in-development/conscious-sedation/>

### ASCS Training for Dental Health Staff

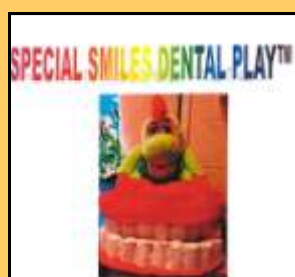
ASCS is collaborating with NHS Education Scotland's Oral Health Improvement Team to provide training to dental health staff.

Two sessions have taken place in Glasgow and Edinburgh and a further four will run in February and March 2017 in Glasgow, Perth, Inverness and Aberdeen.

The training will provide an **understanding of children's play** with the aim of helping dental staff to communicate better with children in their care. To complement this learning, a **Special Smiles Dental Play™ Box** will be loaned to each Board area courtesy of NES.



*Dental staff at the Glasgow training session explore how to use play to communicate with children. Training days for 2017 will be advertised via the NES portal*



*Each NHS Board will get access to a Dental Playbox courtesy of NES*



# Play works! Preparing a Child for Hospital Treatment

Deborah Brown, our Area Officer in Tayside writes:

**'I recently provided play support using ASCS's Hospital Play Box** Resources for a pre-school child in preparation for a major operation. The support was provided within Langlands Nursery Class in Forfar where Emily is a pupil and involved an **initial planning meeting with Emily's** mum Laura and nursery staff.

It was agreed that play sessions would take place as free play activities within the playroom and all children would be able to join in should they wish to do so. This approach ensured Emily was not singled out in any way and would give her the opportunity to take part in a relaxed and familiar environment alongside her peers. She particularly enjoyed reading the book **'Teddy Goes to Theatre'** by Jane Donnelly and could relate the story to her own experience. Many children engaged in various aspects of the Hospital Play Box with medical dressing up outfits and role play activities proving to be the most popular. Children dressed in doctors and nurses outfits could be seen at the snack table, while surgeons and anaesthetist busied themselves in the story corner and construction area. The children enjoyed administering injections and other procedures to one another, as well as willing staff members, making the whole experience great fun.

Nursery staff continued to extend the activities setting up a Hospital corner within the playroom. They **investigated the children's ideas and** interests further by looking at x-rays and developing an interactive wall

display with velcro x-rays of different parts of the body.



An interactive wall allowed children to display Velcro x-rays of different parts of the body

Laura feels the support offered by Action for Sick Children Scotland has been helpful in preparing Emily for hospital treatment. She said,

**"The sessions have provided an opportunity for Emily to understand and prepare for going into hospital. She recently chose to take her special hospital toy and hospital band to nursery for show and tell and said she wanted to tell the other boys and girls about going to hospital. I was so pleased about this. I have also found the parent support and phone calls very valuable, especially the information about children's rights when in hospital and the right to have a parent with them at all times."**

Contact ASCS for more information about our Hospital Playboxes

## User Participation Toolkit

ASCS has been described as *the bridge* between the user (children, young people and their families) and the provider - that is health care services.

For services to be aligned with need, **it is vital that patients' voices are** heard and used to shape the development and delivery of services. All providers have a duty to engage children, young people and their families so that services reflect need and to develop strategies to take this forward. The Scottish Government **Consultation on Children's Rights and Services Planning** document noted:

*'Public authorities should consider how to meaningfully engage with,*

*and support the participation of children and young people in the preparation of children's rights reports.'*

ASCS has recently been involved in delivering three engagement events for professionals, parents and carers and 3<sup>rd</sup> sector organisations in partnership with the Royal College of Paediatrics and Child Health (RCPCH). To facilitate the engagement process we have developed a participation toolkit to assist in engagement with stakeholders. This will be sent to Participation Leads in health boards and voluntary organisations.

Anne Wilson Development Officer

ASCS is grateful to the Scottish Government which provides Children, Young People and Families Early Intervention Funding.

