

The National Council for Child Health and Well-being

Wednesday 28th November 2018, 10:30 – 13:00

The Council room, Royal College of Nursing, 20 Cavendish Square, W1G 0RN.

Honorary Chair: Dame Marion Roe, DBE

Honorary Secretary: Fiona Smith

NOTES

1. Welcome

Dame Marion Roe opened the meeting and welcomed council members. She expressed her deep appreciation to RCN and more particularly to Fiona and her team for hosting and organising the meeting.

Attendees:

Dame Marion Roe, Honorary Chairman, NCCHW

Fiona Smith, Professional Lead for Children and Young People, Royal College of Nursing

Xavier Baby, Nursing Coordinator, Royal College of Nursing

Dr Spencer Pitfield, PACES Sheffield

Sarah Earle, Research Director, Open University

Julia Walport, Chair, The Amber Trust

Samantha Barber, CEO, Batten Disease Family Association

Sheila Catchesides, Carer, Freddie Farmer Foundation.

Danny Catchesides, Founder and Trustee, Freddie Farmer Foundation

Margaret Jeal, Chair, Action for Sick Children

David Bloomfield, Chief Executive, National Migraine Centre

Sophie Dodgeon, Policy and Campaigns Manager, Rainbow Trust Children's Charity

Anne Harris, Director of Care, Rainbow Trust Children's Charity

Rachel Perrin, Partnership Development Manager, Family fund

Ryan Nibloe, Project Assistant, National Children's Bureau

Gillian Mulloy, Grants Fundraiser, Ronald McDonald House Charities

Anne Ward, Head of UK Development, Ronald McDonald House Charities

Jane Gates, Director, Sebastian's Action Trust

Candida Hazard, Trustee (Oncology), Sebastian's Action Trust

Joanna Heath, Project Manager, Children's Heart Federation

Jackie Dallard, Development Manager, Children's Heart Federation

Karen Dobson, Newlife Consultant Nurse, Newlife – The Disabled Children Charity

Sophie Dziwinski, Programme Manager, Roald Dahl's Marvellous Children's Charity

Tim Soule, Programmes Officer, Roald Dahl's Marvellous Children's Charity

2. Apologies

Holly Shaw, Nurse Advisor, Allergy UK

Julie Watson, National Specialist Advisor, Children & Young People, Care Quality Commission

Lizzie Chambers, Director of Research and Programmes, Together for Short Lives

Lynn Hoppenbrouwers, Strategic Health Lead, Contact

Ella Arbelaez-Rodriguez, Training Manager, Challengers

Janice Allister, Adviser in Child Health, Royal College of General Practitioners

Jennie Albone, Acting Head of Programmes, Booktrust

Norma Jun-Tai, Lecturer – Health Play Specialists, National Association of Health Play Specialist
Lynn Davinson, Children's Services Manager, CQC
Lynn Regent, CEO, Anaphylaxis Campaign
Sally Vincent, Young People and Families Service Manager, Arthritis Research UK
Sue Flohr, Policy Officer, British Dyslexia Association
Davina Richardson, Children's Continence Advisor, Disabled Living
Sue Jennings, The Royal College of Psychiatrists

3. Notes of meeting held on 5th September 2018

Confirmed as an accurate record of the previous meeting.

4. Matters arising

A reception was held at the House of Commons on 26th of November. Newlife released a press-release and report (see attached).

5. Correspondence

There was no correspondence to be shared with the group.

6. Presentations & discussion

6.1 Migraine in Children and Teenagers

David Bloomfield, CEO, National Migraine Centre.
(Please find presentation attached)

David Bloomfield highlighted his own migraine experience and the results of years of research on migraine. Migraine is an extremely common condition, which is not often well treated because it is difficult to be diagnosed by GPs.

The presentation focused, primarily on migraine in children and teenagers:

- Youngest reported age of diagnosis of migraine 4 months!
- 2 peak ages: 5 years and 10-12 years
- Roughly equal in boys and girls before puberty
- More girls than boys after puberty 3:1
- Approx. 10% of school children have migraine
- About half have their first attack before age 12
- In some, the predominant symptom is abdominal pain –headache may be absent
- Link with travel sickness and cyclical vomiting

It is not always a headache and it is stigmatised just like mental health. The causes can be complicated and migraine can be triggered by environmental changes to a sensitive brain. Poorly managed migraine attacks can lead to reduction in school performance, interruption of normal activities, anxiety and depression. Early diagnosis, means it can be managed/ treated with self-help, routine and medication. Migraine can be a disability and all schools need to care and make some adjustments. Teenage girls are more prone to migraine than teenager boys. New treatment is available on the market but not yet approved by NICE.

Action: Circulate National Migraine Centre funding link - **XB**

Action: Send information to FS for cascade to school nurses -**DB**

6.2 Children's Heart Federation

Johanna Heath, Project Manager, Children's Heart Federation
(Please find presentation attached)

The federation main activities are:

- Campaign for children with congenital or acquired heart conditions
- Provide an information service for families
- Provide INR machines where they are not available through the NHS
- Take part in research projects relevant and of benefit to children with heart conditions
- Produce the children's book Rosie goes red, Violet goes blue
- Run a Molly's Dollies service

One in every 133 children in the UK is born with a heart condition; about 1/3 will need surgery as an infant. Most surgery will leave a scar or scars.

Molly's Dolly was created to help children to understand their scars and for cardiac nurses and specialists to explain treatments. It is also a soft and cuddly friend to the child, who enjoys and shares her/ his company with others. Molly's Dolly has become very popular. Molly's Dolly is free of charge to children specialists and can be purchased online.

Next steps:

- Plan to supply dolls to each cardiac ward.

6.3 Supporting the siblings of seriously ill children

Sophie Dodgeon, Policy and Campaigns Manager, Rainbow Trust Children's Charity
(Please find presentation attached)

What do we know about the need?

- 49,000 children living with life threatening and life limiting conditions in 2009-10 in UK. 40,000 in England.
- Prevalence known to be rising – as result of medical advances. Demand for our support is rising.
- Our best estimate is that there are at least 32,000 families where one or more siblings have a seriously ill brother or sister.
- More than 70% of children's hospices who responded said that demand for sibling support has increased over the last three years.
- 60% of children's hospices said that that they offer more hours of support than three years ago.
- Only a third said that they can 'always' meet demand.

Schools can be a great break but can also be challenging. Great examples such as sibling support groups in hospital and in families were mentioned.

What needs to change?

- Provide guidance to Clinical Commissioning Groups and Local Authorities to highlight the need to commission local sibling support.
- Champion an early intervention and family resilience fund to increase the availability of family services such as sibling support.
- Support schools to play a fuller role in identifying and meeting the needs of siblings of seriously ill children

- Implement a clear referral pathway for mental health support for siblings if their needs escalate.

7. Any other Business

FS raised concerns about Public Health funding cuts, which are greatly impacting on the number of Health Visitors and School Nurses and ultimately, on access for children, young people and families.

Action: Feedback, evidence, case studies and stories to be sent to FS - **All**

8. Focus of future meeting:

20th February 2019: 10:30 - 13:00

- Doreen Crawford, Neonatal nursing
- Holly Shaw, Allergy UK
- Carol Williams, Special Needs School Nursing

9. Dates of future meetings:

- Wednesday 8th May 2019
- Monday 16th September 2019
- Thursday 12th December 2019