Welcome to the CEN Winter Newsletter. This edition will summarise the latest developments within the network as well as current topics of conversation and upcoming plans.

Children with Exceptional Healthcare Needs National Managed Clinical Network

Corona Virus (COVID-19)
The CEN team want to firstly acknowledge the unprecedented and fast moving COVID-19 situation which is unfolding in the world around us and the challenges this is causing for NHS staff and families, especially those who include a child or young person with exceptional healthcare needs. These are challenges which we have never experienced before, but the dedication and hard work of professionals, key workers and community spirit has also never been more apparent.

We discussed whether or not to send our newsletter, but decided that we would; to share some good news and updates on how the CEN NMCN are responding to the outbreak.

CEN have populated pages on the website with guidance specifically on COVID-19 and for mental health and wellbeing in general which may be useful to you and your patients and their families (https://www.cen.scot.nhs.uk/advice-and-support-including-covid-19/) we have also been Tweeting relevant information and support via the @CYPNMCN twitter account.

We hope you and the ones you love all stay well throughout the COVID-19 pandemic and please do not hesitate to contact us if we can be of assistance.

CEN Staffing

CEN welcomed Miss Shelley Heatlie as Programme Manager in February, Shelley was previously an Assistant Programme manager working alongside the CEN network and is committed to driving the network forwards.

Chris Williamson also joined CEN in February as Programme Support Officer replacing Jamie Nimmo who secured a Programme Manager position within another clinical network—the Network wishes Jamie well and sends thanks for his support over the past year and welcomes Chris to the role.

Dr Susan Buck’s three year leadership of CEN will be coming to an end in May 2020.

What is Anticipatory Care Planning?

Anticipatory Care Planning (ACP) is a person-centred, proactive approach to care planning. It uses a “thinking ahead” approach to planning future care, which can benefit quality of life and meaningful outcomes. ACP involves understanding the individual’s situation, their health conditions and the wider holistic aspects of their care needs and experiences. The process can help individuals and those close to them to navigate health and care systems and make informed choices about their care and preferred place of care.

ACP can be especially beneficial when an individual’s health and care needs become more complex, however the process can be started at any stage of the person’s care journey. The Anticipatory Care Plan is a live record or document, that should be developed over time through evolving conversations that take place with regards to an individual’s health and care needs. This requires collaborative working and shared decision-making by all involved in the care pathway. The ACP should be reviewed and updated as the individual’s condition or personal circumstances change, also as different areas of health and care needs take priority.

It is important to remember that creating an ACP is an optional process and that all sections of an ACP may not be relevant at that time. ACP can be defined as a proactive and mutually collaborative approach to achieve meaningful care experience and outcomes.

Your child or young person may also have a Children and Young Person Acute Deterioration Management plan (CYPADM) in place. All patients will have an eKIS, (electronic key information summary) which can be found here: https://www.enable.org.uk/get-support-information/families-carers/future-planning/emergency-planning/

It may be helpful to think about an emergency carers plan (ECP), should an essential carer become unwell. Guidance about these can be found at https://www.enable.org.uk/get-support-information/families-carers/future-planning/emergency-planning/

You can also visit Healthcare Improvement Scotland’s anticipatory care planning toolkit here: ihub.scot

CEN Annual Event

The CEN Annual event took place on 27th Feb 2020 in Glasgow, the theme of the event was ‘Communication, Co-ordination and Compassion’.

Talks on the day covered a range of topics from Ethics, Housing, CAMHS, Young Carers and internet safety to name a few.

There was also a presentation from a CEN young person and the parent of a CEN young person which both illustrated the need for good communication, co-ordination and compassion.

Key messages from the day will soon be available on the CEN website.

CEN would like to thank all of the speakers and market place contributors for their hard work on the day at what was an excellent event.

Children and Young People Acute Deterioration Management Plan (CYPADM)
Clinical Audit System Update
Following detailed discussions with the National Child Health Commissioner’s (CHC) group, the critical importance of CEN data collection on CAS and the benefits that could come from having accurate Scotland wide CEN data were recognised. The CHCs were very much in support of the need for National data collection across Scotland and have agreed to complete this as a quality improvement project within this year. The reasons for supporting this project were noted as being; lack of current national data, growing number of CYP with exceptional needs who are living longer, high resources required to care for this group, increased vulnerabilities of this group of patients and their families due to complexities of conditions and the need to have accurate data for the number of CYP transitioning into adult services to ensure accurate planning for services.

The aim of this project is to have all NHS Boards trained and capturing essential CEN data by the end of 2020.

Summary of Kindred Advocacy Service
Exceptional Families Project (Oct 19-Jan 20)
We have provided support to 65 families during this time who meet the CEN criteria. The families are from the following 12 local authorities:

<table>
<thead>
<tr>
<th>Local Authority</th>
<th>Number of Families</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aberdeen</td>
<td>1</td>
</tr>
<tr>
<td>Edinburgh</td>
<td>17</td>
</tr>
<tr>
<td>Fife</td>
<td>22</td>
</tr>
<tr>
<td>Midlothian</td>
<td>6</td>
</tr>
<tr>
<td>Perth &amp; Kinross</td>
<td>1</td>
</tr>
<tr>
<td>South Lanarkshire</td>
<td>1</td>
</tr>
<tr>
<td>Aberdeen</td>
<td>1</td>
</tr>
<tr>
<td>East Lothian</td>
<td>2</td>
</tr>
<tr>
<td>Falkirk</td>
<td>2</td>
</tr>
<tr>
<td>Glasgow</td>
<td>5</td>
</tr>
<tr>
<td>North Lanarkshire</td>
<td>1</td>
</tr>
<tr>
<td>Scottish Borders</td>
<td>4</td>
</tr>
<tr>
<td>West Lothian</td>
<td>2</td>
</tr>
</tbody>
</table>

Total raised in increased annual income for families is: £241,525 (an average of £3,715 per family)

The main sources of funding were:

- Carers allowance: 6
- DLA (care): 10
- DLA (mobility): 7
- Family Fund: 2
- Other grant: 12

The following assistance was provided with statutory services:

- 11 families were supported with information and advice regarding education.
- 5 assisted with respite
- 4 Section 23 assessment
- 12 Self Directed Support
- 8 families assisted with adaptation to housing
- 5 families assisted with moving house

Kindred Advocacy Service
Kindred works in partnership with CEN to provide emotional and practical support to families of children with exceptional healthcare needs across Scotland. We are able to assist you with organising statutory care packages, benefits (including Disability Living Allowance) and funding for aids and equipment.

Contact us and we will call you back: telephone 0800 0315793 or email enquiries@kindred-scotland.org

Website
As always, we welcome any comments and feedback regarding the website. You can visit the site here: www.cen.scot.nhs.uk. If you have anything you would like to share or have any general feedback, please email the team at NSS.CEN@nhs.net.

Twitter
The CEN network is now actively tweeting via the Children and Young People’s NMCNs Scotland.

Follow us @CYPNMCN for all of the latest news and developments in relation to children and young people with exceptional healthcare needs in Scotland. You can quickly search for the CEN-related tweets by using the hashtag #CEN.

Call for New Members
We are always keen to welcome new members to our Steering Group and other working groups. We always aim to have multi-disciplinary, multi-regional representation and are particularly keen to have family members of children with exceptional healthcare needs involved.

If you would like more information or are interested in getting involved with any of our groups, please contact us using the details below.

In our commitment to Stakeholders during corona virus we have postponed all face to face CEN meetings and have created an advice and support page on our website for parents, carers and professionals.

Get involved
Further details can be found on the CEN website: www.cen.scot.nhs.uk

Email us: NSS.CEN@nhs.net

Or phone us on: 0131 275 7612