

**Welcome** to the Association's July newsletter which we hope will update you on ABPN news as well as items of interest to children's nurses and information about study days on relevant topics. It is your newsletter so please get in touch with any comments or items you would like to be included.

As previously mentioned the newsletter editor will be standing down next year and the ABPN really needs a member to take up the challenge so perhaps it could be you! Please take time to read the advert below and think about whether you would like to join the team

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Follow us on Twitter @ABPN\_ChildNurse

## Looking to widen your horizons and share news and good ideas?

### We need **YOU** as Newsletter Editors!

We are looking for bright, interested people who will be able to contribute to the work of the Association of British Paediatric Nurses through helping edit and develop our Newsletter. Note: This role is not remunerated and is done as part of the ABPN Governance and Development Group.

The Newsletter is currently produced 3-4 times a year and it acts as a mean of informing our members of new developments within practice, policy changes, consultations, research opportunities and other items of interest.

Ideally the successful applicants for the role of **Newsletter Editor(s)** will have experience of working within health (clinical or academic) or within a health-related area and with an interest in child health. However, interested applicants who believe that their skills match our brief are encouraged to apply,

There is real potential for this role to be shared allowing individuals to bring their own particular skill set and expertise to the role. For example, we need people with all/some of the following skills:

- searching for interesting news and ideas
- presenting news items in a clear and unambiguous way
- designing and laying out the copy
- liaising with key stakeholders within and external to the ABPN

- keeping to deadlines.

No specific prior experience of producing a newsletter is required although applicants will be asked to demonstrate that they have transferrable skills (e.g., searching databases and/or producing reports, and/or disseminating findings/ideas).

There are number of benefits of undertaking such a role. These include the experience of working with other committed children's nurses and being part of a network of experienced nurses. Other benefits include the opportunity of being able to take the Newsletter forward, contribute design ideas and to be acknowledged as a key person within the Association. The work will also help to raise your profile and the skills, experience and expertise you will acquire will add depth to your CV and this can reap rewards in terms of career progression.

If you are interested, in the first instance, please contact: Katrina McNamara-Goodger

[katrina.mcnamara@icloud.com](mailto:katrina.mcnamara@icloud.com)

## Thesis Help

Can you help Katie with her Thesis by completing a survey?



We would like to invite you to participate in a short survey about how health and social care professionals make sense of and respond to situations involving mothers and their children. To take part you must be over the age of 18 and currently working in the health and a social care sector in the UK.

In total, it should take approximately 5-10 minutes to complete. As a thank you for your time, you will have the option to enter a £50 Amazon voucher prize draw.

To find out more or to take part please follow this link to the online survey:

[https://essex.eu.qualtrics.com/jfe/form/SV\\_8p35rqj0R1vlf4p](https://essex.eu.qualtrics.com/jfe/form/SV_8p35rqj0R1vlf4p)

If you have any questions, please contact Dr Katie Manning at  
[km17504@essex.ac.uk](mailto:km17504@essex.ac.uk).

## NHS Funding for Children's Hospices and Palliative Care in England

NHS England has announced:

- Ring-fencing £25million of NHS funding to support children's hospices in England specifically by 2023/24, increasing annually over the course of this period from this year's Children's Hospice Grant baseline of £12million.
- Running a needs assessment to understand whether additional investment nationally or from CCGs is required where palliative care is provided by other means (NHS trusts or other charities, for example).

NHS England officials have said that they plan to scrap the policy set out in the Long Term Plan of match funding NHS England funding to increases in CCG funding in children's palliative care. Instead the £25m funding will come directly from NHS England.

This was made public last night (1 July) by Care Minister Caroline Dinenage during [a House of Commons debate on children's palliative care](#) secured by Dr Caroline Johnson, Conservative MP for Sleaford and North Hyekham and co-chair of the All-Party Parliamentary Group (APPG) for Children Who Need Palliative Care.

Caroline Johnson MP quoted [Together for Short Lives' recent report](#) on statutory funding for children's hospice organisations. She also pointed out that the bulk of care is provided by families at home and that respite services were essential to the support of families of children with life-limiting conditions. Catherine McKinnell MP, the other co-chair of the APPG, emphasised that care is needed throughout the course of a child's illness, not just at end of life.

In her response, Caroline Dinenage MP, who was wearing a Together for Short Lives pin badge, mentioned last year's [APPG report](#). She went on to highlight the work being done by NHS England, in parallel with its commitments in the Long Term Plan, to support clinical commissioning groups (CCGs) and develop commissioning models specifically for children and young people with palliative care needs. This work includes the pilot of the new NHS England service specification pilot which Together for Short Lives helped to support.

Following a further intervention from Caroline Johnson MP, Caroline Dinenage MP moved on to speak about short breaks and importance of having reliable provision in local areas. She acknowledged that local authorities have a legal duty to commission short breaks, and that many CCGs also plan and fund them for families, but that there was still more to do to ensure that these breaks were reliable and accessible for families. The minister concluded by committing to continue to meet with the co-chairs of the APPG and with Together for Short Lives to look at ways of tightening provision for children with life-limiting conditions and their families.

Clearly, the commitment to invest £25 million in children's hospices, directly from NHS England, will enable this part of our sector to plan its services more confidently. But the commitment to review wider resourcing and develop a more consistent and sustainable funding approach for other children's palliative care services, provided by NHS trusts and others, with commitment from the very top of NHS England, is also a very significant step.

**Together for Short Lives**

Tel 07943534498 Mobile 07943534498 [www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)



Medicines & Healthcare products  
Regulatory Agency

## **Valproate medicines and serious harms in pregnancy: new Annual Risk Acknowledgement Form and clinical guidance from professional bodies to support compliance with the Pregnancy Prevention Programme**

Ongoing patient survey data suggest that more effort is needed by clinicians to achieve full and timely compliance with the valproate Pregnancy Prevention Programme. We have updated the Annual Risk Acknowledgement Form, which should be used during annual specialist review of all women and girls of childbearing potential on valproate medicines (irrespective of indication).

## **Bereavement Pathway following BABY Loss /SUDI**

The National Bereavement Care Pathway (NBCP) aims to improve the bereavement care parents receive after pregnancy or baby loss. It helps professionals to support families in their bereavement after any pregnancy or baby loss. The pathway covers five bereavement experiences: miscarriage<sup>1</sup>, termination of pregnancy for fetal anomaly (TOPFA)<sup>2</sup>, stillbirth, neonatal death, and sudden unexpected death in infancy (SUDI).

The project is backed by the government and has received funding from the Department of Health and Social Care. The NBCP is supported by the All-Party Parliamentary Group on Baby Loss and championed by health ministers. Sands is leading the project

The overall aim of the NBCP is to overcome inequalities and increase the quality in the provision and experience of bereavement care. To achieve this, the project has produced a series of five pathways (relating to the five bereavement experiences above) for professionals to follow.

The desired outcomes from the NBCP project are:

- **For bereaved parents:** increased choices, improved care, improved experience.
- **For frontline health professionals:** increased confidence, streamlined processes.
- **For decision makers:** improved service delivery, increased satisfaction, streamlined processes, improved data quality.

## **Evaluation of the National Bereavement Care Pathway (NBCP)**

### **Final report (Wave two)**

**May 2019**

*“Overall, the care we received cannot be faulted, and we are so grateful to have had this level of care. I truly hope this becomes a national standard that all bereaved parents will benefit from, as I cannot express how much it has helped us navigate through this most difficult time.”*

Parent of a stillborn baby

**Richard Donaldson**

FivewaysNP Ltd

www.fivewaysnp.com

@FivewaysNP

## Local Government Association (LGA)

We have all heard a great deal about increasing problems with the mental health of children and young people. The LGA recently published a report looking at ways to prioritise early help. Improving children and young people's mental health and emotional wellbeing: Findings from the LGA's peer learning programme. Ref code 15.4

The LGA's Children and Young People's Mental Health and Emotional Wellbeing Peer Learning Programme looked at how to prioritise early help and free up acute care for the most vulnerable in order to achieve change; supporting councils and their local partners to learn from each other, and from other councils across the country.

Eight councils and their partners took part in two learning days and a visit to another council, gaining further knowledge and understanding on how to tackle their local issue.

[info@local.gov.uk](mailto:info@local.gov.uk)

## Physical activity helps children to deal with life's challenges

A new survey from Change4Life and Disney UK has found that less than half of parents are aware that physical activity can build children's self-confidence (49%), reduce anxiety (47%) and improve their self-esteem (46%).

Only one in six thinks that physical activity can help children develop attributes that help them to cope with set-backs.

Evidence shows that children and young people who are more active have more confidence, higher self-esteem, less anxiety and stress and better social skills – attributes that can help them deal with the challenges they face in daily life. Positive attitudes towards physical activity have also been associated with children being happier.

The UK Chief Medical Officers recommend that children do at least 60 minutes of moderate to vigorous physical activity every day, yet just 20% of boys and even fewer girls (14%), are meeting this target, despite 95% of children saying that they enjoy being active.

Public Health England is launching the 10 Minute Shake Up campaign with Disney and Sport England this summer. Getting children into the habit of doing fun, short bursts of activity can set them up for life by improving not just their physical health but also helping them develop key life skills.

For more information, please search 'Change4Life' online or visit: [www.nhs.uk/10-minute-shake-up](http://www.nhs.uk/10-minute-shake-up).

## Amendment to the Mental Capacity Act becomes law

On 16th May 2019 the Mental Capacity (Amendment) Act gained Royal Assent, following a contested journey through Parliament. The Act provides an update on the 2005 Mental Capacity Act, a piece of legislation which sets out what should happen when a person lacks capacity to make one or more decisions for themselves.

The Act will introduce the Liberty Protection Safeguards (LPS), which is a new model to safeguard and protect individuals who lack capacity and may be deprived of their liberty during their care.

The need for an amendment

The current system, the Deprivation of Liberty Safeguards (DoLS), has received significant and widespread criticism for creating a huge burden on the system and not adequately protecting vulnerable individuals.

The DoLS will run alongside the new LPS for a year after implementation, to ensure that all cases are transferred effectively. In a contrast to the DoLS, the new LPS model will apply from age 16, which is an important and welcome move as it extends protections to 16 and 17 year olds.

CDC is part of a working group with the Department for Education to ensure that the new statutory guidance and code of practice will meet the needs of children and young people and their families.

The journey from Bill to Act

The Act was subjected to intense scrutiny throughout its development. Campaigning efforts from across the sector led to substantial changes being made to the original Bill.

The statutory guidance and Code of Practice for both the Act and the Liberty Protection Safeguards, which will set out how the legislation should be implemented, are under development and consultation from across the sector.

[www.legislation.gov.uk/ukpga/2019/18/enacted](http://www.legislation.gov.uk/ukpga/2019/18/enacted)

## Care Quality Commission (CQC) Report

CQC calls for independent reviews of children and young people held in segregation

We've published a report giving early findings from our review of the use of restrictive interventions in places that provide care for people with mental health problems, a learning disability and/or autism.

The report focuses on 39 people who are cared for in segregation on a learning disability ward or a mental health ward for children and young people.

From an information request sent to providers, we were told of 62 people who were in segregation. This included 42 adults and 20 children and young people – some as young as 11 years old. Sixteen people had been in segregation for a year or more – one person had spent almost a decade in segregation.

We make a number of recommendations, including a call for independent reviews of every person who is being held in segregation in mental health wards for children and young people and wards for people with a learning disability and/or autism.

Telephone: 03000 616161

Fax: 03000 616171

Or write to us at:

CQC National Customer Service Centre  
Citygate  
Gallowgate  
Newcastle upon Tyne

[CQC@public.govdelivery.com](mailto:CQC@public.govdelivery.com)

## Membership

Congratulations to Freda Long who recently celebrated her birthday.

As ever please let Jim Robinson know of any address or email address changes.

Jim can be contacted on [membersABPN@yahoo.co.uk](mailto:membersABPN@yahoo.co.uk) so feel free to drop him a line.

## Study Days/Conferences



Entries are invited from nurses working in the community and primary care to promote any area of their clinical practice that reflects the Conference themes.

### **Day 1: Voice to Action**

### **Day 2: Excellence in Action**

Standard delegate rate: £199 per day.

### **To book your place: Online via Billetto**

visit <https://billetto.co.uk/e/qni-annual-conference-2019-tickets-334470>

You will have the option to book day 1, day 2 or both days through the Billetto link, please ensure you select the right rate.

### **Invoicing**

If you are unable to pay online, there is an option of requesting an invoice to be sent out to your employing organisation. For more information please email [events@qni.org.uk](mailto:events@qni.org.uk)

Please note there is a £15 admin fee per invoice which is non-refundable.

The conference also includes an exhibition of voluntary and private sector organisations.

If you need any further information please do not hesitate to call me on 020 7549 1407 or email [farida.barlas@qni.org.uk](mailto:farida.barlas@qni.org.uk)

Registered charity number 213128

<http://www.qni.org.uk/>

## **Advanced Communication Course**

A 2 day Advanced Communication Course running 10<sup>th</sup> and 11<sup>th</sup> October, Mercure Hotel, Walsall, West Midlands. This course is designed for health care professional working with CYP and their families Cost £600

For details contact Dr Lisa Kauffmann/Nicki Fitzmaurice  
[info@reachcommunication.co.uk](mailto:info@reachcommunication.co.uk) . Tel 07775947563



## **Safeguarding Children and Young People in the NHS**

Working across multi-agencies to improve assessment and referral processes, implement change and tackle societal challenges faced by vulnerable CYP

**Tuesday 24th September, Birmingham City Football Ground, Birmingham**

■

This new networking forum will bring together those working with children and young people to ensure that the necessary processes and procedures are in place to protect them. Don't miss this unique opportunity to come together with colleagues working across the multi-agency teams, which implement and improve safeguarding, across the country.

Improve your knowledge and leave motivated to:

- **Progress assessment and referral processes**
- **Collaborate with MASH**
- **Work with your team to improve processes for neglect**
- **Build a plan to implement changes to the child death review**
- **Set up the Child-Protection-Information System**
- **Make improvements in relation to prevent**

### **Book your place**

<mailto:SBK.Healthcare@dotmailer-email.com>

You can secure your place by; [registering online](#), emailing the [bookings team](#) or giving us a call on [01732 897788](tel:01732 897788).

### **Reserve a place**

Alternatively, if you'd rather make a no obligation reservation for the time being, then please email the [Leonna Kettle](#) with your name, job title and contact details and we will make sure to save you a place.