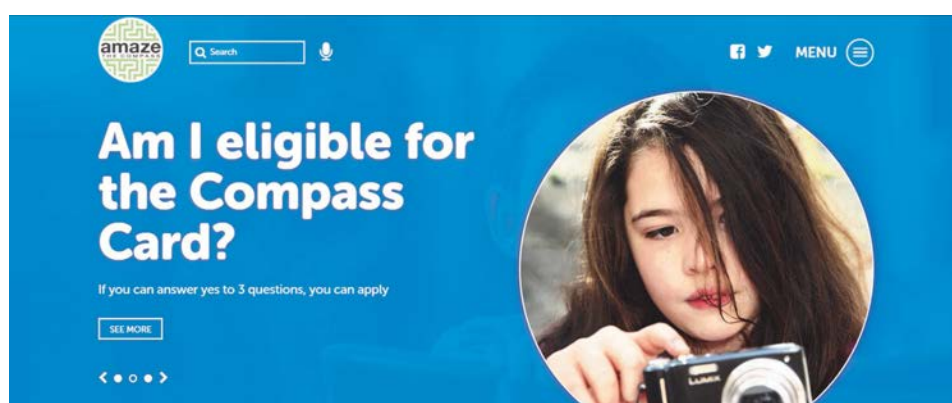


Compass website goes live

Our brand new Compass Card website makes keeping up with our leisure offers easier than ever.



Launched in December last year, our new site at www.compasscard.org.uk works with our Compass Card apps for Brighton and Hove and West Sussex to make finding leisure offers simple and straightforward.

You can already see all our Compass Card offers via the Compass Card app if you have an iPhone or Android smartphone – but the new website means you can also see all the information on PCs and laptops, as well as iPads and tablets and other smartphones too. It's brilliant for planning trips out with the family that make the most of Compass Card savings, or if you want to check out offers while you're on the move.

You'll find everything you need to apply for a Compass Card on the new website, including registration forms and tips on how to fill in the forms, along with the latest information on

leisure-related news and events, a feedback form, all our Compass Card literature and much more. There are also links to the Amaze website if you want to find out more about our other services.

The website also has its own blog. The first post includes a short 'talking heads' video of people saying what they think of the Compass Card and we'll be posting about topical issues regularly. Check out our blog for carers which gives you plenty of ideas about how you can look after yourself and our next blog which is packed full of ideas for the Easter holidays.

If you've got ideas for the blog, or if you've got comments on the new website, we'd love to hear from you. Just fill in our online feedback form (you'll find it in the menu) or email us at compass@amazebrighton.org.uk



Julia draws a huge crowd at Info Fair

Nearly 200 parent carers made it to our Info Fair last November and many of you bought your kids along too.

Julia Donaldson proved to be a great draw, with families (such as Vicky and Audrey, pictured) queuing down the hall to get signed books or buy tickets for the tombola of goodies kindly donated by Julia.

We were delighted to see so many parents at our workshops on 'positive behaviour' and 'getting SEN support in school' and our stall holders from local SEND services seemed equally pleased with how the day went – as they told us they were busy talking to parents all morning.

As one parent explained on our feedback postcard: "Great fun, great people, fantastic support, lots of information."



Special school mergers moving forward

Brighton & Hove City Council has begun formal consultation on its proposals to merge some of the city's special schools. Read more detail about the proposals on page 6 and on the Local Offer at www.brighton-hove.gov.uk/localoffer. And have your say on the proposed changes at www.brighton-hove.gov.uk/special-school-PRU-consultation



Brighton Table Tennis Club joins the Compass

Brighton Table Tennis Club provides top class coaching for local young people and has grown to become one of the country's biggest table tennis clubs. It runs sessions for young people of all ages and backgrounds, including **sessions for people with Down syndrome**, girls-only sessions and junior sessions.

Compass Card holders pay concessionary rates (£2 instead of £4) and carers go free. Brighton Table Tennis Club is at The Fitzherbert Centre, 36 Upper Bedford Street, Brighton BN2 1JP. Visit www.brightontabletennisclub.co.uk for more information, or call 01273 670145.

For full details, see the Compass Card app on your iPhone or Android smartphone – search 'compass card' in the App Store or Google Play and download the Brighton and Hove version. Or see the 'offers' page on the new Compass Card website at www.compasscard.org.uk



Parent carer Nikki Morgan and friend after the race.

Half runners raise £7k

A huge thank you to our 18 Brighton Half Marathon runners who battled the wind and rain on Sunday 26th February to raise a staggering £7,000 for Amaze!



Clare Anderson raised a whopping £4k for Amaze.

We'd like to name check them all: Beyrom, Caroline, Clare, Chris, Dervish, Donna, James, Jemma, Kelly, Grant, Greg, Keith, Shell, Simone, Steve, Nikki, Pat, and Rachel.

Special mention to James Mullan, Amaze's quickest runner with a time of 1 minute, 26 seconds, and to Clare Anderson, captain of The Dyke Golf Club Ladies Team, who has raised a further £2,000 making her overall total £4,000.

Thanks again team: your weather-beating efforts will help to keep Amaze running.

Fact sheets very popular with parents

We've had over 1100 downloads of our new fact sheets for parent carers since their launch at the end of August 2016. Covering over 40 subjects including specific conditions and hot topics like 'SEN Support in school' and 'Coping with stress', the fact sheets are available on our website at www.amazebrighton.org.uk/resources/publications/fact-sheets



Brighton budget reprieve for youth services and short breaks

Proposals for severe cuts to youth services in Brighton and Hove were reversed in a seven hour budget meeting at Hove Town Hall on 23rd February.

Before Christmas, the council had proposed savings of £800,000 on youth services – which included cuts to council-run and voluntary sector services.

Following months of protest by young people and their supporters, the budget meeting restored most of this amount, though there will still be cuts of £205,000 a year. We don't know what these smaller cuts might mean for youth services used by young people with SEN and disabilities yet but we'll let you know as soon as we hear.



Other amendments to the budget mean that less money than expected will be cut from grants to charities and community groups and some funding has been restored for respite care for children with disabilities (see page 9 for more details on this).

CCG funds mental health training for parent carers

Amaze is delighted that the local Clinical Commissioning Group has earmarked some children's mental health funding for work with their parents too. What's more, Amaze has a share of this funding to offer courses to parent carers over the coming year – see page 15 for details.

The grant shows that the CCG recognises that parents are the primary support for children with mental health needs. It also shows just how valuable it has been to have a PaCC rep on the Mental Health and Emotional Wellbeing Partnership, speaking up for the parents' role in caring for children with mental health issues. See page 10 for more on mental health.

Great news for the newsletter

Kind donors mean Out of Amaze stays in print for now

You may remember that in the last issue we told you we were going to have to stop printing and posting copies of this newsletter to you directly, unless we found some extra funding. We're delighted to tell you that the funds we needed have indeed come our way – as you can no doubt see if you're reading this on paper!

Firstly a donor (who wishes to remain anonymous) gave us a very generous £5,000. This **anonymous donor** felt very strongly that the information in Out Of Amaze needed to remain accessible to all families and that we shouldn't have to rely on people having access to the internet or a smartphone. This unexpected donation will help ensure we can keep printing and posting this

newsletter to families for the time being.

Secondly, our wonderful supporters at **Wellesley Charitable Foundation** have very kindly agreed to continue their £1,000 sponsorship for each newsletter. The Foundation, which has been helping to fund our newsletter for a couple of years, shares our goal to support disadvantaged children. They have also funded some of the smaller organisations linked to Amaze.

If you are involved with a local organisation that needs funding, you



can find out more at their website: www.wellesleycharitablefoundation.co.uk

We're sincerely grateful to both these funders for helping us to continue printing and posting the newsletter. But we won't just be celebrating – we plan to use the opportunity to update our mailing lists and make sure we make the money go as far as possible.

Help us keep print costs down: if you no longer want a copy of this newsletter, or if you're getting more copies than you need, please email charlotte@amazebrighton.org.uk

In loving memory

of Hazel Herovitsch, Amaze helpline worker, volunteer and all round champion of resilience, 30.11.58 – 8.1.17



Everyone here at Amaze was deeply saddened to hear of Hazel Herovitsch's death from cancer on the 8th January. Many parents will have benefited from Hazel's support over the years, first in her volunteer role with Amaze, then as an Independent Supporter and, more recently, as a helpline worker.

Hazel first contacted Amaze when she and her family moved to Brighton from Austria, where she'd home-educated her youngest son who has autism. Having found Amaze's support helpful, she started to volunteer for us.

Hazel did our 'Insiders' Guide to Bringing Up Teenagers with SEND' course, where she learnt about applying a resilient approach to life. She wholeheartedly embraced this approach and put it into practice in every aspect of her life. And she asked that in remembering her we took some time to tell you how valuable the resilient approach was for her.

Hazel lived by one of the fundamental principles of resilience – **enlisting support when she needed it**, for herself and for her son and

recognising that it is a sign of strength, not of weakness, to know when she needed help.

She showed enormous commitment to parenting her son, who she had a very loving and close relationship with. She was good at **cherishing the positive** in her own and her son's life – even when times got tough. She said she learnt that it's not worth railing against the things you can't change or do anything about – that it's best to accept them – and instead she put her energy into things where she could make a difference.

We will remember her as a very positive, loving and dynamic woman with a passion and commitment to improving the lives of families.

Hazel knew the importance of **sorting out the 'basics'**; she worked hard to ensure her son had the right support in place when he moved out of the family home into his own flat. She showed great respect for the staff team who support him, sharing her unique knowledge of what works best for him, but appreciating what each of them brought into his life.

Hazel's family were hugely important to her; both her sons and her husband were with her when she died at home.

But she also felt a real connection and sense of belonging to the wider community of families with children who have SEND. She had a lot of good friends who she'd met through Amaze.

She was a parent representative for the Parent Carers' Council (PaCC) on both the Autism Strategy Working Group and the Adult Learning Disability Partnership Board for a number of years, sharing her experience to try to influence and improve services for families.

She was a volunteer for Mymarc, helping at the 'Make Your Mark' art workshops for young people with SEND, sharing her passion for art. She was a talented artist herself, with a great eye for colour and design. Anyone who knew Hazel could see she had a wonderful, individual style of dress.

Hazel had **many coping strategies** to deal with the challenges that life threw at her. She was always committed to learning and open to trying something new and she had a great sense of humour.

Hazel will be very much missed and our thoughts are with her family and friends at this sad time. But for those of us who were lucky to have known her, we will remember her as a very positive, loving and dynamic woman with a passion and commitment to improving the lives of families whose children and young people have SEND. Hazel's approach to life can serve as an inspiration to us all.

Hazel asked for any donations in her memory to go towards Amaze's work supporting parent carers to build their resilience. You can donate at www.justgiving.com/fundraising/forhazelhero

If you want to learn more about how to build a resilient approach to life as a parent carer, why not book on to a free Amaze Insider Guide course – see page 15 for details



Futures peer support

Amaze is delighted to announce a brand new way of providing support for young people with SEND

This time last year we told you that our vision for our work with young people for the future would be to have a team of young volunteers who could give peer support to young people aged 14+ with SEND. The good news is that thanks to funding from The American Express Fund, the Insurance Industry Charitable Foundation, Newman's Own Foundation and the Skills and Opportunities Fund, we can do just that!

Amaze's Futures Project will train young people aged 18+ with and without SEND (special educational needs and/or disabilities) to be volunteer peer supporters to young people with SEND aged 14-25.

What is peer support?

Peer support happens informally in all areas of life. The idea is that people who have been through similar experiences can provide support to each other based on their shared understanding.

What might a peer support volunteer do?

The team of volunteer peer supporters will get to know and support young people aged 14-25 with SEND to help them develop their skills, explore their interests and think about their future goals. This might include help to try out new activities, access training, volunteering and employment opportunities or develop new social networks.

Are you 18+ and would like to volunteer on the Futures Project? Or are you 14-25 and would like to get support from the Futures Project? If so, call Sue on 07483 111648 or email sue@amazebrighton.org.uk

Farm Fridays

Fridays have become an eagerly awaited day of the week for Lee, a pupil at the Cedar Centre, Brighton when he goes off to work with a local farmer.

FarmBuddies, who arrange social care farming programmes across the South East, visited the farm at the end of last year to check on outcomes with the farmer, who said, "Lee loves bedding up the animals, collecting apples for the pigs, scraping the muck in the yard, mowing the grass, bringing in the Christmas trees for customers, filling up his wheelbarrow with veg from the field, making a bonfire and we have a proper sit-down lunch in the farmhouse."



"At any sign of a change in mood, his carer takes him for a long farm walk and after that he's fine again."

The school adds, "Lee has improved his team work, time management, social skills and career focus, the plan now for 2017 is very encouraging; he will continue here with Fridays at the farm but will also attend some sessions at a mainstream school and agricultural college."

The school requested a repeat farm programme in 2017 and thanks again to the financial support of the Starr Trust this has been arranged.

If you know a young person who might be interested in getting work experience at a local farm, contact Farm Buddies on 01420 538793 or visit www.farmbuddies.org.uk

Varied farm programmes are available from 9.

SEND changes

What's happened and what's coming?

Over the past year Brighton & Hove City Council has been planning and consulting on changes to special educational needs and disability (SEND) services proposed by the SEND Review. These are big changes and the path towards them is quite long; here's what we know so far.

BHISS (Brighton and Hove Inclusion Support Service)

We told you in the last newsletter that this service had just started, pulling together the existing learning support services (such as the old ASCSS), community CAMHS, behaviour support and the educational psychology service. BHISS is now settled in at Brighton & Hove Music & Arts Building in County Oak Avenue and the contact number is 01273 293481. The service links to every school (and pre-school) in the city and mostly works by advising school staff how to help your child best, but will also offer some advice to parents.

Changes to pre-school support

PRESENS, the Preschool Special Educational Needs Service, has changed. The support they provide for children with SEND in local pre-schools and nurseries is now part of BHISS, but what is offered should be more or less unchanged. The side of PRESENS that offers places for some children in the year before Reception at Jeanne Saunders or Easthill Park stays the same for now, but plans are being made in the longer term to move to one site, as part of an inclusive nursery. We don't yet know where this will be as there's a couple of options. This won't affect any children currently at Jeanne Saunders or Easthill.

Another change expected soon is that Downs View and Hillside schools will be able to take children with the most significant needs from as young as two, if parents want this option and it is agreed it would suit the child. This will go ahead from September if it is signed off by the council's Children's Committee in March.

Changes to special schools and PRU

This is the most major area of proposed change and is moving more gradually to allow for lots of consultation and planning. The plan is to keep the same number of special school places, but to organise them differently. There has been consultation about closing Patcham House school and in March the Children's Committee will decide whether to take the next steps towards closure in July 2018.

The plan for provision for children with SEMH (social, emotional and mental health needs) is to bring together Homewood College, the Connected Hub and the PRU, though not necessarily all on one site, and much thought is going into how it would meet the varied needs of this group of children and young people.

The aim for the city's other special schools is to bring together Downs Park and Hillside in the west and Downs View and the Cedar Centre in the east of the city to offer a more integrated provision for children with learning difficulties and complex needs. Looking at how to merge or link each pair of schools is complicated, but there is a shared aim for the city to offer the best it can for these children and their families at a time when money is tight for all public services.

The council launched a consultation on the reorganisation of special schools on 13th March. You can give your views at www.brighton-hove.gov.uk/special-school-PRU-consultation

A new special facility

The plan to set up a new special facility like the ones at BACA, Hove Park and Longhill is progressing well. Three schools are interested and we'll know which gets the facility this summer. This isn't a direct replacement for Patcham House, but will offer a positive option for a number of children, including some that might previously have been offered a place at Patcham House.

Amaze and PaCC work together to keep the views of parents and the interests of families at the centre of all the planning around these changes. If you have concerns or questions please get in touch.

Congratulations to Autism Aware schools

Four local schools have completed the challenging Autism Aware Award over the past year. This demonstrates their commitment and knowledge about supporting pupils with autism. So a big cheer for St Luke's, St Peter's, Downs Junior and Hove Park. Seven more schools have signed up to work towards the award this year: West Blatchington, Varndean, Carden, St Nicolas, Goldstone, Stanford Infants and Hertford Juniors.

"This Award makes me feel safe because I know that the school care about me being here" - Year 6 girl with autism



Parent Carers' Council

STRONGER TOGETHER



PaCC Champions take centre stage at Info Fair

Amaze's Info Fair in November gave PaCC the perfect platform to show our appreciation for people who work with our children

Every year our PaCC awards allow us to celebrate those people who go the extra mile to support us and our kids. At this year's Amaze Info Fair we were delighted once again to be able to publicly thank those people and services that may sometimes be overlooked. And to have the chance to highlight the vital role that people like our school taxi drivers provide; often going way beyond the requirements of their job description to support our children.

Caroline Lucas presented the awards to this year's very deserving winners for 2016 in four categories:

- **Health:** the winner was Louise Loadsman, Special Needs School Nurse, Seaside View.
- **Education:** the winner was Natalie Stone, Early Years Worker
- **Voluntary category:** the judging panel decided on two winners from local parent-led support groups, as both entries were equally strong.

Sally Howell won for her outstanding work with Brighton Pebbles and Kerry Korkunc (pictured, with Caroline Lucas) for her fantastic work with Sweet Peas.

- **Social Care:** again, the judging panel agreed to have two winning teams as nominations were equally strong. The award went to Taxi Driver and Escort, John Whittan and Ann Head, and to Taxi Driver and Escort, Wayne Brookes-Baker and Denise Bell.

Do you know a PaCC Champion for 2017? Nominate them at <http://tinyurl.com/paccchampions17>



Families need more help with move to adult health services

In September 2016, PaCC asked some parent carers about their experience of accessing health care services before, during and after their children's transition to adulthood.

Our consultation indicates that while there are many services on offer, some services may be either underused or not widely promoted. One parent commented, "Not sure what's out there as my child becomes older".

The timing of the transition from children's health services to adult services can be complex. To navigate through such a difficult time, **parent carers would like to receive more information on what is available and better communication between services.** One parent said, "Because my son has Asperger's Syndrome and because of his age, the increase in care needed is not acknowledged, as he attends university - it is as if all doors are closed".

The majority of parent carers who took part in our consultation were **not aware that they could ask their young person's GP for a longer appointment to put together a Health Action Plan.** The plan is very important as it holds information and details about the young person's health needs and the services required.

A group of young adults, who were also able to comment on transition and health care services, suggested **people should be registered as having a learning disability with their GPs.** That in turn would flag up the need for a longer appointment and generate a proper Health Action

continued overleaf



....More on help with move to adult health services

Plan which should be updated with yearly follow-up appointments.

The same group of young people felt that **the way annual check-ups are organised needs to improve**. They suggested that looking at pictures of things that were going to happen during check-ups could improve communication during the appointment. This is also a time where more difficult questions could be asked, for example about cancer screening and sexual health.

We've passed on parent carers' and young adults' recommendations to the local Clinical Commissioning Group (CCG). We'll make sure that parent carers and young adult voices are listened to and contribute to improving transition services across the city. You can read the full report including more information about how to access Health Action Plans at: www.paccbrighton.org.uk/resources/reports

PaCConnect on social care

Our **PaCConnect meeting** in November focused on social care. There was a good turnout of parent carers and professionals included Regan Delf, Assistant Director of Health, SEN and Disability; Carl Campbell, Team Manager at Seaside View Child Development Centre; and Claire Brunt, Acting Team Manager of Residential provision. Key themes were Direct Payments, residential care, transition to adulthood and extracurricular support. The issues raised have helped to inform our work around the budget – see opposite. To view the minutes, please visit our website at www.paccbrighton.org.uk/what-we-do/pacc-connect-events



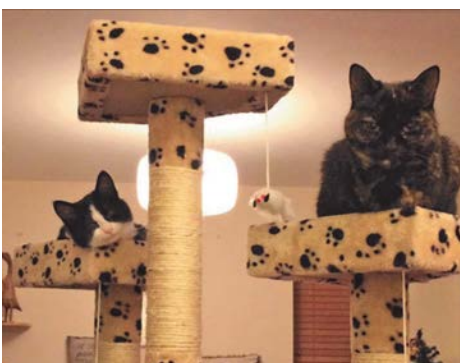
Meet the PaCC pets

Say hello to the furry and feathered friends who make a difference to the lives of our PaCC parent reps

We all know pets can have a really positive effect on family life. They can help you get fit, relieve stress and give you something to talk about. So we thought it was high time three of our parent reps' unsung heroes had their moment in the spotlight.

Sammy - owners Lisa and Eli Russell

"This little budgie brings lots of joy and is a gentle and entertaining companion for my son. They go to bed at the same time and keep each other company at night. Eli loves birds and chose a budgie as a pet 'because they look like they're smiling and they can talk'".

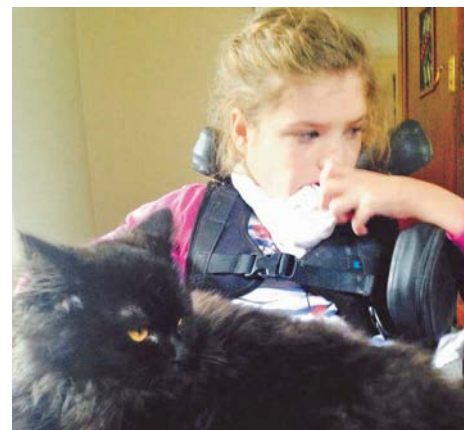


Ruby - owners Amanda and Livvy Mortensen

"Ruby is a star feline companion and snuggles up to Livvy when she is having a bad day of seizures."

Molly and Bella - owner Helen Arnold-Jenkins

"Hello there, I'm Molly and this is Bella! We do our very best to keep everyone calm in the home; we give great cuddles and are both really good at helping with homework (by sitting on it). We guard L by sleeping on his bed at night: 'purr-fect' guard cats, you might say!"





Latest on Brighton's budget

In December, Brighton and Hove City Council announced that they needed to make £24.3m worth of savings in 2017-18 to balance their budget.

The budget proposed £596k worth of savings to be made across SEN and disability services including a proposal to restructure residential short breaks provision to allow for more long-term/full time residential support in the city.

As in previous years, PaCC issued a detailed PaCC Position Statement which set out our concerns about the council's proposals affecting families with disabled children, see www.paccbrighton.org.uk/what-we-do/pacc-position-statements. We also made a very short film to highlight our worries and Fiona England (the Chair of the PaCC) and Rachel Travers (CEO of Amaze) met with various councillors to explain how vital short breaks are to families who are often struggling to cope with daily life.

We are delighted that some of our concerns have been heard and several councillors used PaCC's arguments when debating the budget at the full council meeting on 23rd February. This led to a Conservative amendment to the budget being agreed which asked for an increase to investment in Direct Payments for families by £150,000 next year.

This is excellent news for local families and PaCC will be following up with the Direct Payments team to ensure as many families as possible can benefit from this investment.

However, we are still concerned that Children's Disability Services will need to make £596k of savings next year. And whilst we are supportive of the strategy to try to accommodate children who need full time care nearer to their families within the

city, developing the right provision will take time, so we have expressed concern that the savings target is premature.

We have had reassurance from Regan Delf, Assistant Director of Health, SEN & Disability, that the proposal will not in any way reduce the number of bed spaces available for overnight respite care, as we know several families who don't feel they are getting enough short breaks, or have been waiting too long to get any help and are finding they can't cope.

We have had reassurance that the proposal will not in any way reduce the number of bed spaces available for overnight respite care.

PaCC has agreed to help Naomi Cox, Head of Disability Provider Services, to set up a working group to look at how short breaks services, including residential and non-residential options can better support (more) families and we will update you on this work in our next edition.

Other proposed cuts

Other large savings proposals were put forward and debated including



cuts to the city's youth service, social work teams, early help for families where children are 'at risk', and some services for adults with learning difficulties. Following a large campaign, led by young people themselves, the majority of the cuts to youth services were overturned as was the cut to the council's Integrated Team for Families which provides 'early help' support to families who are particularly in need.

You can find the council's press release here: www.brighton-hove.gov.uk/content/press-release/budget-agreed-201718. Papers detailing the original budget proposals can be found in the Council and Democracy section of the Brighton & Hove website or via this shortened link: <http://tinyurl.com/jtpxrq9>. You can read about the proposals for SEND/disability services on page 123 of the report.

At the time of going to press, we know that Brighton and Hove's Clinical Commissioning Group (CCG), which determines how resources for health services are spent, also has to make considerable savings on its budgets for next year, but we do not yet have details of these. We'll keep you informed as we hear more.

Make your views count. Join the PaCC by emailing admin@paccbrighton.org.uk or tell us what is concerning you at www.paccbrighton.org.uk/get-involved/give-us-your-views
You can also join our closed Facebook group at www.facebook.com/groups/parentcarerscouncil



Positive changes in mental health

There are big changes afoot in the way mental health and wellbeing services are delivered to children and young people in Brighton and Hove and PaCC is at the centre of a group shaping these changes



Though CAMHS (Children and Adolescent Mental Health Services) is often the only support which comes to mind when we think of our children and young people seeking extra help for their mental health and emotional wellbeing, there are a number of local voluntary organisations such as the YMCA, Right Here, Safety Net and Dialogue, that also support kids who may be having tough times mentally or emotionally.

PaCC representatives are currently sitting alongside CAMHS, managers of voluntary sector organisations and local commissioners within the Mental Health and Emotional Wellbeing Partnership Group, making sure the parent voice is heard, respected and taken into account during discussions about the future development of mental health services.

Some good things are already happening as a result of the group. For example, a recent CAMHS trial placing primary mental health workers in three schools (Cardinal Newman, Patcham High School and Dorothy Stringer) was deemed so successful that it's being extended to all secondary schools soon. And they're

looking at how to link all the city's primary schools to this scheme too.

Secondly, Amaze has been given some funding to run courses for parent carers of children with mental health issues (see page 15). And the latest news is that there'll be a new Community Wellbeing Service for children as well as adults starting in June - more on this in our next issue.

At the forefront of future mental health proposals considered by the group is a drive for standardisation. This might mean that a child or young person with particular mental health needs can expect the same level of support, no matter which organisation they are working with. Or that they can expect to hear the same kinds of language from the professionals they encounter. The group is also looking at standardising the way parent carers can give feedback about services and ways of improving communication between different mental health service providers.

We know that changes like these, alongside easier, more child-friendly access to services, are long overdue. For far too long mental health has been the poor relation of physical health services in terms of funding. Together with service providers, PaCC is driving forward positive change within this very normal, but often misunderstood (and at times scary) part of our children's lives. Read more about our work on mental health in future issues.



Marion wins Parent of the Year award

Congratulations to our very own PaCC Steering Group member Marian Tipler, who received a well deserved award for being Parent of the Year at the Argus Community Star Awards, run by The Argus.

One of our fabulous partner groups, Brighton Pebbles, also received an award for The Youth Group of The Year. Brighton Pebbles supports families with SEND children in the community with outings, drop-ins, Mums' lunches and more. Visit www.brightonpebbles.org.uk for more information.

Or read more about the Community Star awards on the Argus website at www.theargus.co.uk

PaCCConnect on inclusion in mainstream schools

Our next PaCCConnect will look at inclusion for SEND Children in mainstream schools. It's on **Wednesday 5th April** from 10am to 12 noon in the Conference Room at Community Base, 113 Queens Road, Brighton BN1 3XG. Come for coffee from 9.30am.

More details will follow via email and Facebook (join our Facebook group at www.facebook.com/groups/parentcarerscouncil). Please email admin@paccbrighton.org.uk if you'd like to attend this event.

Ask an expert

Philip Warford of Renaissance Legal and Sav Kanagasundaram, parent carer and helpline adviser, answer your questions.

"I feel pulled in every direction at the moment and it is getting me down. Everyone says make time for yourself but I don't have time."

Sav says:

"Finding a little time for yourself can feel impossible when you are a parent carer. When your child is there they take your full attention. And if you get any time without them there's a million things to do whether that's work, chores or giving some attention to other family members. But if everyone relies on us, it's vital to look after ourselves. And small things can make a big difference to how we feel."



"Small things can make a big difference to how we feel."

"Carve out a few moments every day to clear your mind and slow down a bit. You could just sit down with a cup of tea and your feet up. But for an even stronger impact you could meditate. That can be as simple as a few minutes of conscious breathing. Breathe in for the count of seven and out for eleven. Five minutes of this conscious breathing reverses the stress reaction in the body. If you want a guide for fitting short meditation into a busy life try a free app like Headspace. A bit of physical activity each day has also been shown to have a big impact on our stress levels. Work out how and when you can grab those few minutes each day."

"At least once a week, find time for doing something you enjoy. What is a thing you love doing that makes you feel like yourself, not mum or dad? If it used to be going to gigs and that's not practical at the moment, could you listen to some favourite music? And not just in the background – stop and enjoy it for a few tracks. Can't afford a spa? How about a luxurious bath once a week? Get out for a walk with a friend. If you can, join a group that does the thing you enjoy. You are more likely to keep doing it if you do it with others. Getting together with other parents can give you a lift too. Amaze has contact details for local parent groups."

"And build a proper treat for yourself into your plans once in a while. This may take a bit of setting up, you might need to enlist the help of others, but it will be worth it. We are all entitled to a bit of pleasure in our lives and it will sustain you to keep caring for others resiliently."

"My daughter has special educational needs and is about to turn 18. Can we still make decisions for her?"

Philip says:

"Determining whether your daughter can make decisions for herself at 18, when she is an adult, is extremely important especially as she has special educational needs and might be vulnerable. The ability to make her own choices and decisions is referred to as mental capacity. The Mental Capacity Act 2005 (MCA) sets out the overriding principle which is that, as an adult, we must always presume that someone has the mental capacity to make decisions for themselves, unless it can be proven that they lack the ability to do so."



"If it is determined that at the age of 18 all steps have been taken to facilitate mental capacity to make particular decisions and it is found that your daughter's mental capacity is lacking, the MCA sets out who, and in what circumstances, other people can make decisions for her."

"The 'decision maker' will then be able to make the decision in question and the MCA states that the decision made on behalf of a person who lacks capacity must be done, or made, in her best interests."

"The decision maker will depend on the type of decision to be made and the particular situation, and they could be you, a carer, health professional, an attorney under a Power of Attorney or a deputy under a Court of Protection Order."

"If it is found that your daughter has mental capacity, then we would recommend that she considers creating a Lasting Power of Attorney (LPA). This document delegates authority to another person (probably you) to make decisions on her behalf as and when you need to. This might be now, if she becomes unwell, or in the future, if the need arises. A LPA takes nothing away from your daughter but can be a very useful document if capacity is lost or fluctuates in the future."

For individual legal advice call Renaissance Legal on 01273 610611 or visit www.renaissancelegal.co.uk NB: Compass Card holders get a 10% discount on fees.

Planning for the Future workshop

Thursday 30th March, 10am to 12.30pm at Community Base, 113 Queens Road, Brighton, BN1 3XG.

Come along to Phil's free 'Planning for the Future' workshop at Amaze for more information about mental capacity, Power of Attorney and Court of Protection. To book, you can email info@amazebrighton.org.uk or call 01273 323832.

Everyday magic

The right therapies can work magic on our kids' ability to learn the skills they need for everyday life.

Most children seem to reach major milestones effortlessly. When our child has additional needs, however, getting them to say words, take steps, sleep soundly, keep friends or just stay well, can feel like a challenge well beyond our skill set. Therapy can help when we don't know where or how to start.

What is therapy?

Therapy is a way of making life better by doing things or thinking differently. Therapies are interventions: the 'added extras' that help your child stay well, grow stronger and get better at everyday things, when they aren't doing as well as their peers. Therapies can be exercises, programmes, treatments, different approaches, and might include using special 'kit' like adapted cutlery or seating systems. It can be talking or other ways of communicating like Makaton or PECS. Therapy can be medication and getting that right. It's worth making the most of appointments to really get a handle on what you can do.

"It was teaching me what to do that made the big difference for both of us"

Before appointments

Write down your concerns and take these with you. Keeping a diary and sending in a 'pen picture' ahead of time, detailing how things are for your child right now can help focus the discussion.

Try and arrange appointments at times that suit your child; if they're tired in the afternoon ask for a morning appointment.

Be prepared for clinics to run late;



take snacks and activities to keep them occupied. If your child is at their best, the therapist is more able to make an accurate assessment

During the session

Include your child as much as you can: if possible, encourage them to explain in their own words how they feel. You might be surprised about what's most important to them and what they would like to be able to do or change.

Ask questions: whether you are worried that it takes your child longer to pick up new skills or that they are socially awkward, it will help you both to make sense of the problem.

If you don't understand, your child won't either so keep asking: explanations need to be simple and strategies must be straightforward.

Find out what you can both do at home between appointments. Check that you understand what you will be doing and why. If the advice sounds counter intuitive, ask why it will work. It's much harder to take a different approach and embrace new ideas if it doesn't make sense.

- ask your therapist to give real examples, and show you what they mean
- get them to rehearse with you and practise until you feel confident
- make sure you will get a written copy of the recommendations
- ask for help if getting hold of resources or equipment might be tricky
- get details of useful websites and online resources
- if trialling a new treatment, be sure you both agree how to report unexpected side effects
- Check how your child's school or nursery can play their part and how you'll both be kept in the loop.

Between appointments

Build any exercises or strategies into your daily routine: often you can harness and adapt everyday activities to embrace and practise these new approaches.

Enjoy yourselves: if you can make it fun somehow, the therapies will be more enjoyable and more effective.

Take it easy sometimes: remember, not every moment needs to be filled with purposeful activity. Give your child time to relax and play.

"To start, I felt really impatient. I wanted to believe the therapist would have Jo talking in a few weeks. We're not there yet. But the picture cards help a lot"

Be realistic: it's what happens day in day out that matters most. Until it feels like second nature, doing things and thinking differently can feel like hard work. Any new approaches need practice - lots and lots of it - so don't expect to see big changes quickly.

Be kind to yourself. Take a longer view: quiet optimism and patience will make a difference. With practice, we can all be our child's best therapist.

Sibs Like Us

Why do we need siblings groups and what happens at our group, Kids Like Us?

The sibling relationship is often the longest lasting family relationship, longer than that between parents and children. Siblings of disabled children need to **learn coping strategies** that they can use when they're adults and may take on care and support roles for their brothers and sisters.

At Kids Like Us, children and young people learn and practice strategies to help them to manage difficult situations. They **identify the people who can support them** at home, at school and in their community.

Siblings' needs often come second to those of their disabled brother or sister, due to the extra caring demands placed on their parents and the limited support available for many families. Sibling groups like ours say, 'This is something that is just for you: your needs matter too.' Siblings want to **be acknowledged in their own right** as children and young people and also

for the role they play in their families, something which is often overlooked by schools and service providers.

Kids Like Us facilitator, Ruth Sullivan, uses art, crafts, games and group discussions to help children open up about their own circumstances. Together, they talk about some of the difficulties they encounter.

"Isolation seems to be a big issue," says Ruth. "As one young person put it, 'it is easier to stay in.'" Another common problem is being hurt by their sibling "although they don't mean it". Siblings can also feel left out, or that they're missing out on things and they sometimes feel guilty about their brother or sister.

But it's not all difficult stuff. Kids Like Us also encourages children to think about and **recognise the positives**, as well as the challenges of having a brother or sister with additional needs. And best of all,



siblings have a break, free from their responsibilities and get to have fun with kids like them. Parent, Becca, said, "It was Amaya's first time at anything like this and she loved every session. Talking about her own situation with others who understood stirred something within her and the facilitators, Ruth and Ellen, were amazing. Amaya felt safe."

Kids Like Us has so far been a big hit with families who tell us their children love meeting and making friends with children with similar life experiences. We'd like to thank the Chalk Cliff Trust for helping us to fund the siblings group. If you've got an 8-13 year old sibling who'd be interested in joining a future siblings group, let us know by emailing info@amazebrighton.org.uk

Newman pulls out all the stops to get Amber on the slopes



This year, Cardinal Newman's annual ski trip included its first disabled skier, Amber Woolnough.

Deputy Headteacher, Paul Miller,

who organises the trip, was very keen to make the trip work as well as possible for Amber:

"We had to do a lot of work with the tour company to make sure we could get an instructor and all the necessary equipment and I went out to the resort beforehand to check the hotel's accessibility for Amber's wheelchair. I also worked with the tour company to make sure the long coach journey to the resort from the UK was possible."

Linda Fairbairn, who heads up Newman's SEN team, worked with the family to prepare Amber for the trip emotionally and in terms of friendships, and to ensure they had a full-time helper ready.

Amber's mum, Fungai, paid the standard cost of the trip: the school paid for the additional equipment and Amber's personal instructor, Gianna, and for her helper for the week.

Amber says, "The ski trip was amazing. I had a fantastic time on the slopes and the sights were beautiful. The staff were friendly and kind and it was very accessible. I also enjoyed just swimming and hanging out with my friends."

Mr Miller says Newman will definitely do it again. "It was a great experience for Amber and for the other students who went on the trip with her."



Get your face on for Amaze

We have launched a **new viral fundraising campaign for 2017** called **Amazing Face**. It's a tongue-in-cheek make-up challenge suitable for all ages: just get your nearest and dearest to make you up from behind and post the results online - the crazier the better! There are some great photo examples here www.justgiving.com/campaigns/charity/amaze/amazingface or you can find Amazing Face on YouTube. Get your face online and help us make this thing go viral by nominating friends and family to take part too.



Music to our ears

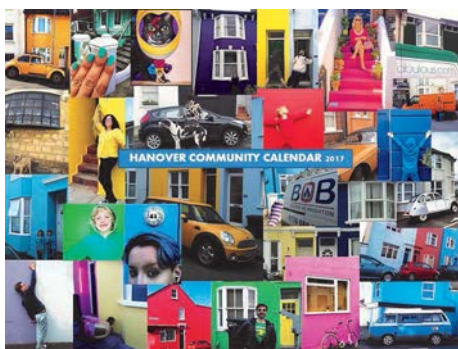
Lisa FitzGerald and the Angel Voices Choir, directed by Eileen Aiviss, **raised £477** for Amaze at their Children's Christmas concert on 8th December. The concert was held at St Nicolas Church, Portslade and included popular festive pieces and audience participation. Thank you to everyone who took part.

Colour matching catches on in Hanover

Our fundraiser and Hanover resident, Nicky Bagilhole, **raised over £5,000** for Amaze before Christmas by designing, producing and selling a colourful calendar with neighbour, Andrew Short.

The Hanover Community Calendar features vibrant photos of Hanover residents matching their cars and outfits to the colour of their houses.

Nicky says, "It was a photo sharing concept that started on Facebook and immediately caught the imagination of the creative people on the hill. Thanks to everyone who took part and to our kind sponsors and advertisers."

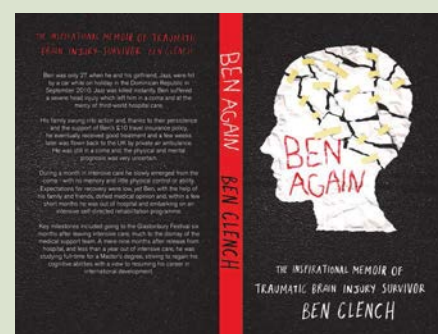


Ben, again

A new book about surviving traumatic brain injury by Ben Clench, son of Amaze's Trustee and Chairman, Hugh.

Most of the children and young people that Amaze works with have conditions or additional needs that they were born with or developed early in life. But we know a few young people who have had to learn to live with a new condition or illness later on, such as acquired brain injury.

At 27, Ben Clench was hit by a car in Santo Domingo in the Dominican Republic. He suffered a serious brain injury and was in a coma for a month.



Six years on, Ben has made fantastic progress and has written a book called 'Ben Again' about his memories of what happened, coming out of his coma and his recovery. It is brutally honest in parts, tragically sad, yet funny too with lots of reflections about health services provided both in the Dominican Republic and in the UK.

It's about how Ben became Ben, again. How he regained as much of the Ben that he could, including a trip to Glastonbury and doing a second Masters degree. He's come a long way, but there is still some road to go.

You can read an excerpt and buy the ebook from Unbound at <https://unbound.com/books/ben-again> or buy a Kindle or paperback edition on Amazon at: www.amazon.co.uk/dp/B01NBW3IJW

Live and learn with Amaze

Our courses, workshops and events are designed to keep you informed and help you cope with your life as a parent carer or as a young person with additional needs. Here's what's coming up soon and how to book...

Workshops

Planning for the future - Mental Capacity, Power of Attorney and Court of Protection

Thurs 30th March, 10am to 12.30pm

At 16, the law says our children have the right to make decisions for themselves whenever possible, but how and when as parents can we act on behalf of someone who may not be able to make decisions for themselves? Phil Warford from Renaissance Legal explains this complex topic in a way we can all understand.

"It was very helpful. Philip has a great deal of expertise in this field – and obviously has families' needs in mind."

Fun Things To Do – What's on offer for young people?

Tuesday 13th June, 4.30 to 6.30pm

This leisure information session gives lots of tips on how young people in the city can get out, have fun and make new friends.

Both these workshops take place in the Conference Room at Community Base, 113 Queen's Road, Brighton BN1 3XG.

Longer courses

Amaze is delighted to have been awarded some funding from the CCG for the year ahead to offer courses that will help parents support their children's mental wellbeing. There will be a mix of courses parents have told us they find useful and some new ones developed with parent input.

Triple P Teens - Friday mornings starting 28th April

Triple P Stepping Stones – autumn term, dates tbc

Triple P courses focus on positive parenting and supporting your child with their behaviour. They are always in demand. The Teen course suits parents of young people age 11/12 to 16. Stepping Stones is for parents of 2 to 12s. Amaze Triple P courses are co-delivered by a professional and a parent carer.



Insiders Guide to bringing up children with ADHD - Tuesday mornings starting 9 May

NEW! Insiders Guide to bringing up children with ASC - Thursday mornings starting 8 June

Insiders Guide to bringing up under 12s with SEND – autumn term, dates to be confirmed.

NEW! Insiders Guide to bringing up children with Anxiety – autumn term, dates to be confirmed.

Insiders Guide courses focus on what it means to be a parent of a child with extra needs. They aim to build your resilience so you are well placed to enjoy the journey bringing up your children. The courses offer a mixture of practical skills for things like dealing with professionals, ideas to help you understand your child's particular needs, as well as time to look at how it feels to have a child with those needs and how to build your own resilience. All Insiders' Guide courses are co-delivered by a professional and a parent carer who has been there too.

"Best things for me were meeting people who understand, the information available and what I learned about myself and coping strategies."

To book on a workshop or course please email info@amazebrighton.org.uk or call the Amaze helpline on 01273 772289.



Happy birthday to us!

Amaze is turning 20 this year and to celebrate, we hope to raise £20,000 to work directly with young disabled people in their 20s. We want to help young people to gain additional skills for independent living, employment and volunteering.

We hope you will get involved. Look out for details of forthcoming celebration events in this newsletter or on our website.

We would also like to hear from any local companies that might like a mutually beneficial partnership. Just contact Nicky on 01273 234014 or nickyb@amazebrighton.org.uk

Journey 2 Employment

Possability People's Journey 2 Employment (J2E) programme **helps disabled people** or those with long term health or mental health conditions **to identify and overcome their barriers to work**. The courses support people to develop self confidence and recognise what they have to offer employers as well as learning new skills. And there is ongoing support after the courses to help people progress and move towards work when they're ready. Possability People have so far helped 50 disabled people into work across Brighton and Hove.

Recruit Ability, in partnership with Brighton & Hove Chamber of Commerce, is working with local businesses to help them recruit disabled people to real job vacancies. If you would like to find out more, call 01273 208934 or email work@possabilitypeople.org.uk

Spill the beans for the Compass Card!

Amaze wants to know what you think of the Compass Card in Brighton and Hove.

We've recently launched two short surveys – one for parent carers and one for young people and we'll use the results to help shape the way forward for the Compass Card – from the potential offers we target next, to the way we communicate with you. We've kept the surveys as short as we possibly can – they should only take a few moments to complete – so please take the time to fill one in for us and ask your young people to do it too.

Everyone who fills in a survey will be entered into a draw for £50 worth of Love2shop gift vouchers. Closing date is Friday 30th June. We'll report on the results on our website at www.compasscard.org.uk later in the year.



You can find both surveys online here:

- Parent carer survey
<https://tinyurl.com/zxvq2qq>
- Young people survey
<https://tinyurl.com/jhbgzy5>

Or you can request a paper copy on compass@amazebrighton.org.uk or by calling the Amaze helpline on 01273 772289.

We'd like to thank Wellesley Charitable Foundation, the charitable arm of Wellesley Wealth Advisory, Sussex-based financial advisers, for its contribution towards the costs of producing this newsletter.

Wellesley Charitable Foundation helps ill or disadvantaged children and their families in Sussex and the surrounding counties. For more information, visit www.wellesleycharitablefoundation.co.uk



We'd also like to thank Brighton & Hove City Council for its vital funding of our information products.



Amaze helpline:

For information, advice and support, call 01273 772289. Monday to Friday, 9.30am to 2pm, Wednesday to 4pm



Amaze

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