



Demelza
Hospice Care for Children

11 June 2020

Dear Parents and Carers,

We understand that this has been a sustained period of uncertainty and isolation for you and your family. This letter addresses Demelza's immediate response to the COVID-19 pandemic, updated information about residential short-break bookings at the Kent and South East London hospices which will also affect some families in East Sussex, and thoughts about Demelza's future services across all areas.

I would really like to talk all of this through with family members. If you would like to join me in a video call I will be sitting with a coffee at 12 noon, and 8.00pm on Zoom on Monday 22 June. The Meeting ID is 813 338 9032.

COVID-19 response

Since lockdown we have changed our services in line with government guidance, including maximising our capacity for urgent priority care. This meant that residential short breaks, day care and care at home services were cancelled.

With careful planning and robust infection prevention and control measures we are currently providing the following services to Demelza children and families:

- Residential stays for children who are unable to be safely cared for at home
- Residential stays and step-down care for children being treated in NHS hospitals (to help free up hospital beds)
- End of life care
- Use of the bereavement suite
- Practical volunteering help and support
- A very small amount of care at home provision where essential
- Opening of limited day activities in the East Sussex building

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Virtual support (via Zoom and telephone) includes:

- Bereavement care
- Daily Music and Art therapy sessions for families and groups
- Weekly Pre-school group - Little Dots
- Weekly Sibling support groups
- Telephone support: including wellbeing calls, a daily support helpline; parent listening sessions, grandparent chat and check in calls

Infection control in residential services

To ensure the safety of the children, families and staff, Personal Protective Equipment (PPE) is worn. This includes staff wearing surgical face masks when delivering care. The measures put in place have been necessary to prevent the risk of the spread of infection. There is an added level of PPE including face visors and gowns for children who have a tracheostomy and those who are ventilated. Staff, families, visitors and children's temperatures are being regularly checked and parent, sibling and family visitor numbers are also very restricted.

All new admissions into Kent and South East London Hospices have to be treated as possible carriers of COVID 19 and therefore, as per government advice, must self-isolate for 14 days (or from 7 days if they become symptomatic). During this period children are cared for in their bedrooms and are unable to access the communal areas such as the sensory room, and lounge areas. Sensory equipment, art materials, toys, iPad etc are brought to their bedroom and their physical, emotional and social wellbeing remains our highest priority.

Current short break bookings

We have been cancelling short break bookings on a month by month basis. We did this because we hoped to be able to recommence these at short notice, but were uncertain of the timeframe. In retrospect that might not have been the most helpful thing in terms of families being able to plan ahead. I am sorry if this has put you in that situation – we're trying to make the best decisions we can in uncertain times.

We are going to be re-opening to some amount of short break provision now that the first COVID peak has passed as I think it is important that we are using every bit of our capacity to provide support. This will be quite restricted however and will in the first instance be allocated to families who are in difficult circumstances rather than by the bookings system, as it is still very difficult to 'hold' capacity to be able to plan forward.

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At present I cannot envisage a time in the immediate future when we will be able to open to 'normal' booked short breaks in the hospices and therefore we will be cancelling all future short break bookings up until the end of 2020.

We will contact every family who has a pre-existing booking and talk through your unique circumstances.

We will keep in touch with all families of course and please do contact us on the Family Support daily help line 01795 845280 between 2pm – 4pm or by email familysupportdepartment@demelza.org.uk

We will put in place a process to utilise our capacity fairly where the need is greatest, prioritising those that require critical hospice care and support.

We cannot make any promises, and there may be restrictions in place if we are able to help, but if we find we have the capacity we will use it.

Please be aware that we are also providing a menu of online and remote support through family support and therapies, which we hope are helpful. If you would like advocacy, emotional, practical or social support, please email the Family Support team. Details of the Family Liaison and Therapeutic groups can be found on the Demelza Families Facebook page and website.

Our practical support volunteering team are also able to provide help collecting pharmacy items, click and collect shopping deliveries for families who are self-isolating as well as collecting and delivering arts and crafts materials.

What's next?

We will be informed by NHS guidance on safe infection control when reviewing and planning what Demelza is able to offer next. We are keen to try and reach out to support as many of our children and families as we can and to be able to provide a more responsive service and be available to emergency requests for support. We are also keen to develop and expand our care at home services. We are looking at restarting care at home in Kent and developing this in South East London. We are re-introducing community packages in East Sussex where it is safe to do so. Each of these will be gradual at first but will build as we go.

We are working on restructuring our services so that they are most helpful. Much of this has had to be done quite quickly, and working with NHS partners to ensure their and our capacity was maximised. Now we are in a more settled period I would very much like to be working with you on what would be most helpful, and involving the parents' forums in some in-depth conversations.

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To begin with, it would be really helpful for me to be able to talk to some of you, to hear how things are and the challenges you are facing, as well as being able to talk through some of the issues in this letter.

As mentioned at the start of this letter, we will set up some Zoom calls – beginning with Monday 22 June. If you would like to dial in I will be sitting with a coffee at 12 noon, and 8.00pm. The dial in details are 813 338 9032.

Hopefully we can do this every couple of weeks, which will help us very much in being able to identify what will be of most help, and where we might be able to do better.

Also since lockdown, our Director of Care Beth Ward has taken planned early retirement. I am delighted to tell you that Liz Bray (previously Lead Nurse) is now Director of Care. If you have any queries, or would like to ask a specific question, please do not hesitate to contact Liz on 07736 275 431 or liz.bray@demelza.org.uk

With best wishes,

Ryan Campbell, CBE
Chief Executive

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