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Our Vision
For life to be better for children and young people who have life-threatening or life-limiting conditions; and for their parents, brothers and sisters, and those who love them, to receive support.

Our Mission
To provide specialist care and support to babies, children, young people and the whole family from diagnosis, during day-to-day family life, times of crisis, end of life and through bereavement.

To influence the care and support provided by others.

Our Strategy 2016-2021: Summary

Our strategy is one of growth. We will double the number of children, young people and their families for whom we provide care. We have to do this because the number of children with life-limiting and life-threatening conditions is increasing, and the amount of care available is already not sufficient.

We will increase the choice of how and where care can be received, shifting some of our focus from the provision of care inside hospices, to hospice care provided in people’s own homes. We have to do this because it is the only way many families can easily receive our support, and because it is the only way for us to rapidly increase the number of families we work with.

We will become properly recognised as the local children’s hospice for South East London, as well as one of the most supported charities in Kent. We will also further develop our provision in East Sussex in partnership with other hospice and children’s services.

Across all of our provision we will become more ‘part of the system’, working with hospitals, community NHS services and charities rather than being seen as separate from other support. This will provide a more co-ordinated and helpful overall experience for families.

In everything we do, whether the direct provision of care to families, delivery of the ‘back-office’ services which make that care possible, in valuing the volunteers on whom we depend, and in our fundraising and charity shops, we will maintain exceptionally high standards of ethics and quality.
Demelza is the local children’s hospice for Kent and South East London, and provides community-based hospice services in East Sussex. We have been operating for 18 years, and are therefore one of the oldest, and largest, children’s hospice organisations in the country. We provide care to around 500 families with life-limited children and young people at any one time. This includes residential respite and short-breaks in our two hospices in Eltham and Sittingbourne, home-based respite in East Sussex, therapy programmes, step-down care (support to help children and families leave hospital and return home or manage a complex episode of care) and end of life care.

We provide activities and therapeutic support to siblings, parents and grandparents, throughout the period in which we are providing care, and afterwards through our bereavement support. We also provide practical assistance to families to help them access the other support they need and overcome the immense challenges they can face. Increasingly, we are supporting young adults in their transition out of children’s services and into adult services, as young people with some conditions are thankfully living much longer.

We only reach about 20% of families who could benefit from our support, and because of advances in medical practice there are more and more families in need. Over the next 10-20 years the number of children who need our help will double. We are working at capacity and currently cannot do much more.

The work we do is getting more and more complex. There are nearly 400 conditions that can limit the lives of children and young people. Some children have conditions so rare they do not have a name. Medical advances and increasing life expectancy has led to more complexity in the needs of the children and young people we care for.

We are well known in Kent, which is where we started providing services. We are not so well known in South East London and East Sussex which began later. This is a problem for our accessibility to families in need, and to the amount of support we get from fundraising to provide services in those areas.

We have recently joined Children’s Hospices across London (CHaL) which is a collaborative of all the London children’s hospices. Working with this collaboration we intend to launch new services in the capital.
Our Strategic Goals
2016 - 2021

Goal 1: Do more
We will care for more babies, children and young people, continue to improve the quality and choice of specialist care and therapies available to families, and demonstrate the difference we make

Over the five years of the strategy, we will:

• Double the number of families with life-limited children/young people that we work with
• Expand Family Support and Therapy services
• Deliver hospital in-reach to support children and families in the neo-natal period
• Deliver a responsive service for children with the highest level of need, in a partnership with the NHS
• Launch community-based groups and support
• Open up our facilities to beneficial community use
• Demonstrate our work against a new outcomes framework

By the end of 2017 we will:

• Launch community-based groups in East Sussex
• Launch volunteer-led family support groups
• Launch a fathers’ support network
• Launch sibling support groups
• Develop new music and art therapy activities, including ‘therapy bags’ for home use, songwriting workshops for bereaved parents and siblings, and music therapy groups for under 5s
• Work with families whilst they are in hospital
• Invite other community-based organisations to use the facilities at the Kent hospice
• Agree an outcomes framework
Goal 2: Care at home
We will provide much more nursing and supportive care in the child or young person’s own home, whilst improving access to amazing facilities at our hospices

Over the five years of the strategy, we will:

• Deliver community-based care in Kent and South East London, as well as in East Sussex
• This will include volunteer-led care and support

By the end of 2017 we will:

• Launch community-based respite and end of life care in Kent
• Work with each South East London borough on a model of joint working in the community
• Agree a way to deliver community-based support across the whole of London, working with partner hospices
• Pilot a model of home-based volunteer support
Goal 3: Excel
We will deliver outstanding quality, with effective governance and infrastructure

Over the five years of the strategy, we will:

• Demonstrate continuous improvement in quality
• Maintain the facilities and infrastructure required to deliver this strategy
• Implement a model of family-engagement which drives every part of our work
• Promote equality and challenge discrimination

By the end of 2017 we will:

• Agree and report against a new quality framework
• Agree and report against a new equalities and diversity impact assessment and plan
• Introduce effective mobile and remote-use technology
• Introduce a business-partner model of financial management
• Develop social media based family engagement networks
Our Strategic Goals
2016 - 2021

Goal 4: Influence
We will improve the overall quality of paediatric palliative care by extending and developing collaborative working with other health and social care providers

Over the five years of the strategy, we will:

• Develop our reputation as a resource for expertise in pre and post-bereavement support and end of life care
• Ensure our hospice care is offered to families within a co-ordinated wider package of core health and social care services
• Contribute our expertise to the development of paediatric palliative care

By the end of 2017 we will:

• Agree protocols for community working in Kent and South East London
• Develop and deliver training packages and commission these to external practitioners
• Develop influencing objectives through engagement with families
Goal 5: Promote
We will raise our profile to better explain what we do, and highlight the extraordinary lives of the children and young people we work with

Over the five years of the strategy, we will:

• Evolve and develop the brand and look of Demelza
• Gain a much higher profile as the children’s hospice for South East London
• Communicate our clear role as an essential partner in paediatric palliative care in East Sussex

By the end of 2017 we will:

• Launch a South East London strategy and campaign
Goal 6: Resource
We will support and develop our staff and volunteers, and raise the money we need to sustain current work and assure our long-term future

Over the five years of the strategy, we will:

• Support a workforce of trained staff and volunteers that meets identified needs for all areas of the organisation
• Deliver a sustainable funding model, with consistent surplus to be invested in the development of care
• Deliver income growth of at least 25% to fund the developments in this strategy

By the end of 2017 we will:

• Develop an infrastructure to expand our learning and development resource
• Increase the number of volunteer hours in direct care by 100%
• Maintain a balanced budget
• Increase non-legacy voluntary income by 10%
• Maintain income from our charity shops and Demelza Lottery in a challenging environment
<table>
<thead>
<tr>
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<th>Activity</th>
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<td>1</td>
<td>Launch community-based groups in East Sussex</td>
<td>Care</td>
<td>Improved individual/family functioning</td>
<td>Service user questionnaire</td>
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<tr>
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<td>Launch volunteer-led family support groups</td>
<td>Care</td>
<td>Improved individual/family functioning</td>
<td>Service user questionnaire, and outcomes star where appropriate</td>
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<td>Launch a fathers’ network</td>
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<td>Better and more timely access to hospice care against needs-assessment</td>
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<td>Launch sibling support groups</td>
<td>Care</td>
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<td>Service user feedback surveys and questionnaires, and feedback from Parents’ Forum</td>
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<td>New music and art therapy activities</td>
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<td>Agree an outcomes framework</td>
<td>Care</td>
<td>Future planning in Care better directed towards outcomes</td>
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<td>2</td>
<td>Launch community-based respite and end of life care in Kent</td>
<td>Care</td>
<td>Achievement of service user directed outcomes</td>
<td>Careplan reviews</td>
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<td>Work with each South East London Borough on a model of joint working in the community</td>
<td>Care</td>
<td>Outcomes to be derived once model(s) agreed</td>
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<td>Agree a way to deliver community-based support across the whole of London, working with partner hospices</td>
<td>Care</td>
<td>Outcomes to be derived once model(s) agreed</td>
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<td>Pilot a model of home-based volunteer support</td>
<td>People and Resources</td>
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<td>Agree and report against a new equalities and diversity impact assessment and plan</td>
<td>People and Resources</td>
<td>Improvements in service access and experience</td>
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<td>Develop social media based family engagement networks</td>
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<td>More effective and better informed development of services</td>
<td>Service user feedback questionnaires and Parents Forum feedback</td>
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<td>4</td>
<td>Agree protocols for community working in Kent and South East London</td>
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<td>Better family experience</td>
<td>Feedback in Careplan reviews</td>
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<td>Develop and deliver training packages and commission these to external practitioners</td>
<td>Care</td>
<td>Improved local practice as a result of training</td>
<td>Post-training participant feedback</td>
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<td>Develop influencing objectives through engagement with families</td>
<td>Care</td>
<td>Outcomes to be derived once objectives agreed</td>
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<td>5</td>
<td>Launch a South East London strategy and campaign</td>
<td>F&amp;M</td>
<td>Greater funding and profile in South East London</td>
<td>Income and marketing reports</td>
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<td>6</td>
<td>Develop an infrastructure to expand our learning and development resource</td>
<td>People and Resources</td>
<td>Staff members and volunteers taking up a wider range of effective training and development choices</td>
<td>Service user survey and questionnaire feedback, Care staff feedback through supervision, and training feedback</td>
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<td>Increase the number of volunteer hours in direct care by 100%</td>
<td>People and Resources</td>
<td>Effective volunteer contribution to Care</td>
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<td>Maintain a balanced budget</td>
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<td>Management accounts Budgets and forecasting</td>
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<td>Retail/F&amp;M</td>
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