



demelza

Circles of Care FAQs



Why are you doing this now?

We know the number of children with palliative care needs is increasing and we are in a position to support more children with serious or life-limiting conditions, and their families. We need to support the most clinically complex children sooner and more often but have also recognised it is increasingly hard to deliver an effective short breaks service to everyone equally due to high demand and a national nursing shortage. Our three **Circles of Care** are focused on being equitable for families with the highest needs. This new model means we can be more responsive and allow our specialist team to provide additional support during times of increased need.

How has Demelza assessed which Circle of Care my family is in?

The Circles of Care have been determined by the needs of the child. Each child has had an assessment by a senior nurse. We have used medical information from different sources such as professionals working with families, Demelza care plans or the Kent and Medway Care Records clinical database (for families living in Kent). Additionally, we have also taken into consideration social factors that may indicate a need for specialist short breaks. We have enclosed a blank copy of our assessment for your information.

Can I appeal this decision?

Yes. If you think we may have incorrectly assessed your family you can appeal, or a professional, such as a social worker or nurse, can do this on your behalf. When you make your appeal, you will be asked to indicate which section of the assessment you feel needs reviewing. All appeals will be reviewed by our senior nursing team which can take up to 25 working days, however we will work to do this sooner if possible. The appeals process is separate from the Demelza complaints procedure and does not affect your right to make a complaint or provide feedback.

Can my family move between Circles of Care?

Yes. We recognise the needs of children and families can change quickly and our new Circles of Care allow us to be responsive and step up our support during times of need and step down again during more stable times. If a family is in urgent need of immediate support, this system allows us to respond and support them. We encourage families to contact us if their needs change and we will contact you at least twice a year as we realise it may be hard to reach out when times are tough. We will continue to carry out annual reviews for all children which may mean children move between Circles of Care or, if they no longer meet our criteria, they will be discharged.

Will some children be discharged from Demelza as part of the new service model?

No, children are not being discharged as part of the introduction of this new service model. Demelza already reviews each child annually against the current criteria and this process will continue. If following an annual review a child is discharged and their medical needs subsequently change, we welcome re-referrals for families and have made our referral process as easy as possible to reassure families that Demelza is here when needed.

Is the introduction of a new service model in response to a shortage of nurses?

We needed to review our service model to ensure we have a reliable, safe and equitable service. It is not in relation to staffing or funding. However, the national shortage of nurses is an on-going challenge for healthcare providers across the UK. Demelza continues to run nurse recruitment marketing campaigns and are continually looking at ways to retain and recruit nurses including reviewing terms and conditions of employment to make us a viable alternative to working for the NHS.

Is this change because Demelza is in financial trouble?

No. We have not reviewed our service model since Demelza was established. The clinical and social needs of the children and families we support have changed and the number of families accessing our services has increased. This new model of care is based on individual need, ensuring the services we offer are meaningful, reliable, safe and well-resourced. This change is not related to income.

Why is Demelza trying to grow the caseload when at the same time restricting services for families who need them?

We know that the number of children with palliative care needs is increasing and we are in a position to support more children with serious or life-limiting conditions, and their families. We need to support the most clinically complex children sooner and more often, which is why our new service model is focused on being equitable for those families with the highest needs. This new model means we can be more responsive and allows our specialist team to provide additional support during times of increased need. We will continuously review how we deliver our services by engaging with families and analysing data.

Will other services be stopped?

No services are being stopped. As part of creating this new equitable model, families will have access to services that are appropriate to their level of need, as set out in Demelza's robust assessment criteria. It does mean not every family will always be eligible to access every service.

I don't know what other services are available to my family, how do I find out?

We have enclosed our Circles of Care brochure which gives an overview of which services are available. The Family Update, sent regularly by email, includes details of our seasonal programme of events, activities and events which is a great way to keep up to date.

To speak to the team about these changes please contact:

Family Engagement Team

Call: 01795 845293

Email: family.engagement@demelza.org.uk

demelza.org.uk

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