

PINNT is committed to supporting members who are affected by the supply issue with Calea. We have also been contacted by non-PINNT members. Below are responses to the questions we have received. Our responses are detailed to the best of our knowledge. We cannot comment on clinical aspects, nor can we pursue individual situations. We are working with all relevant bodies to continually convey the concerns of patients/parents/carers.

What is PINNT doing about the Calea failure to deliver parenteral nutrition (PN) to their customers?

- Firstly, while we recognise that many people are angry and want answers as to why but, we are keen to focus on what is being done now to support and feed/hydrate those who need their PN. We will revisit the 'why' in the future.
- We have responded directly to members who have contacted us.
- PINNT has been able to provide comments to the Department of Health (DoH) working group England, that was set up once this situation occurred.
- We published two letters on our website to members, as we do not hold data on which homecare company members are with, we are unable to post directly to those affected.
- We also sent a letter to Simon Stevens, Chief Executive NHS England and copied in others. Additionally, we wrote to Dr Andrew Goodell, Director General for Health and Social Services and Chief Executive of NHS Wales and copied in others. I can confirm no responses have been received.

Can you tell us more about the DoH working party, who are they and what are they doing?

- Our understanding is that this group is primarily made up of NHS England staff, a list of members has not been published. We also understand that there are at least 4 front line NHS healthcare professionals (HCPs) on this group.
- This group is obviously dealing with an unprecedented situation.
- The group is looking at a situation that is changing on a daily basis.
- Primarily it was important for them to engage with Calea, Medicines & Healthcare products Regulatory Agency (MHRA) and other bodies to determine the extent of the situation.
- Communications out of Calea has been difficult and unreliable, not only to the people they supply to but to NHS England & Wales and HCPs.
- The group is only able to manage the information they are aware of, they are not deciding about individual patient requirements nor what is coming out of Calea. However, not all members on this group are party to other NHS England and Wales activity. The HCPs on the group are there to provide focus and feedback about what's happening for front line HCPs and submit ideas and recommendations for action that could/should be considered. This is in addition to their day job!

Calea said PINNT has a representative on the DoH working group, is this correct?

- No, this was inaccurate information provided by Calea. They have removed the post on their social media page that stated this. PINNT is able to collate and submit questions and feedback from members, currently no formal position is held.

Is it correct that PINNT is receiving updates, why are you not sharing them with members, even non PINNT members who need your support?

- We do receive some updates; they are clearly marked as 'confidential' - 'not for distribution outside the email group' or 'highly sensitive information'. PINNT is taking advice as to what

information we are legally allowed to share with people, and we will continue to provide updates as much as possible. We will not be sharing any ad hoc comments on social media. The information relating directly to clinical care is not information PINNT should be passing onto those in need of their PN.

- PINNT has also spoken to some non-PINNT members and, will not discriminate between members and non-members in difficult times such as this. As with all those involved, we are not able to dedicate all our time to this important issue, even though we would like to.

Why isn't the group arranging for patients to move to other companies?

- The available compounding spaces with other homecare companies has been used.
- Clinicians are being forced to make difficult decisions about the priority of patients. These decisions are extremely difficult for them. While we recognise that everyone with intestinal failure and on HPN is a priority, some will be more in need than others due to clinical conditions. PINNT is not able to comment further on that.

Is there enough capacity elsewhere for those Calea patients who are affected by the supply issue?

- Honestly, currently, no there isn't.

Is it true that those who have been put on multi-chamber bags (MCBs) for four-week are now not able to have them due to a shortage of MCBs?

- We understand that there is a shortage of a certain type of MCB as of 6th August when we prepared these notes, we have no further news on when further stock will be available.

They are saying MCBs for four-weeks, is that really the case, could it be longer?

- Given the lack of compounding capacity, yes, it could be.

Why are the communications from Calea so ineffective? Is it true they are closing?

- The communications from Calea have been a major part of this crisis. It's affected patients/parents/carers/healthcare professionals/NHS England & Wales.
- Closing – no, there are no plans for this to happen.

Why do they ring and ask what we have, they should know – why do they still ring for stock checks?

- Yes, they should, this demonstrates that they are unable to maintain reliable records, also they may not be aware of any deliveries you may have had since they last rung.
- They may be keen to determine if you have had PN/fluids/MCBs from your hospital.
- Stock – this is necessary to ensure that if you do receive supplies (from them or somewhere else) you will have the necessary items to connect/disconnect.

Why isn't anyone taking this seriously?

- PINNT is taking this very seriously, as are all the HCPs involved. Calea realise how serious this is, even if you don't feel that.
- As PINNT is a core group of BAPEN, we are coordinating letters and communications with them too.
- In terms of the government – we don't believe they realise the seriousness of this. NHS England and Wales – they do; but we would like more decisive action and coordinated information from them. The current approach obviously isn't working or getting to the right people. This approach is being reviewed.

What is being done to support our nutrition teams and our healthcare professionals?

- Firstly, we want to thank all the HCPs who are currently overwhelmed with this situation, they are working day and night to do the best they can for their patients. They are endeavouring to manage this during the busy holiday season, normal hospital life and now the additional burden of this situation.
- They will be utilising internal resources as and where they can.

Why is there a variation of information being sent to patient/parents from centres?

- They are accountable to their own Trusts communication teams to ensure what they say is correct and reliable. They do not want to send out any wrong information. Each Trust will have their own policies. They all realise they have a duty of care and that many people will not be happy with the information they need to convey.
- Trusts are having to tell patients/parents information that they 'need' to during this time, not what they 'want' to, they want everyone back on their PN.
- Support is being offered where it can be, we believe this will continue to be an ongoing problem, with staff being under pressure for longer than originally expected.

Is anyone in an official capacity monitoring/aware of what Calea is saying in their Facebook page? It's causing a lot of anger and distress.

- As Calea operate their own social media page, they are responsible for what they post. Where they are issuing general advice or statements, we believe this is being seen by the DoH working group, but they do not have sight of the Calea Facebook page; that does not mean they necessarily agree with what is being said.
- PINNT is aware that some people have come off some social media pages because it's far too stressful. Also, some of the information isn't correct and it's causing extreme distress. Others say it's the only way they find out anything.
- We understand that Calea have a media company managing the page now and will be briefed to provide standard statements from Calea, these may not necessarily be approved by your nutrition support team (NST).

Could this happen to another homecare company?

- All homecare companies are regulated and reviewed; each review is extensive. If all guidelines are followed, we see no reason why this particular situation would be repeated.

PINNT continues to recommend the following:

- Keep all lines of communication open with Calea UK.
- Ensure your/your child's nutrition team and relevant healthcare professionals know if you are not receiving the fluids you are expecting.
- Remember each person on home parenteral nutrition (HPN) has specific needs, your/your child's requirements will vary from others on HPN.
- If you elect to contact the media, focus on your personal situation. Stick to the facts as you know them.
- Contact your MP.

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