

My wife, Jayne, was put on PN towards the last 2 years of her life as this was the only method left to enable her to get the nutrients she needed to live.

In 2003 Jayne was diagnosed with cancer, her treatment ultimately led to her to having a Urostomy and Colostomy due to bladder and bowel failure, though she managed to have a full life until November 2012.

We faced this new development in her fight to sustain life, we were both scared and uncertain of the unknown, we didn't know what to expect but we knew it couldn't be ignored.

As the carer it was sometimes difficult to remain positive, to be the one that always pretended to find the positive in the next news; and now, how on earth was a catheter into the main artery right next to her heart going to help to feed her? Who knew that you could take in your nutritional requirements and fats directly via the blood stream? It was my job to be the calm and the reason and to give plenty of unwavering confidence. . . You can cry on your own when nobody can hear you!

There were many positive aspects to her PN and there were some negative ones too;

On the negative side Jayne was very conscious of infection, particularly as she had to have the catheter replaced twice due to one case of rejection and one of infection, this meant her being extremely nervous of sharing bathrooms or other environments where others may not be so conscious about hygiene.

Things that went wrong occasionally:

Failure to connect the line correctly or air in the line – this was generally user error and mostly occurred when Jayne was tired. It was important that I knew how to connect and disconnect the line and was confident enough to do this, including ensuring everything was wiped down and handled correctly, so that I could step in and support Jayne or fully undertake the task

Supplies failed to be delivered – we were delivered to once a week with a week's supply; on a number of occasions our supplier, failed to supply and this led to panic and concern for Jayne. It was difficult to impress upon these people how important it was, she probably wouldn't have died from one missed night, but the fear and panic caused more issues and as her partner it was distressing.

On the positive side the PN was administered throughout the night, this enabled her to have a relatively normal life during the day, indeed she continued to teach on a daily basis and was doing so 48 hours before she passed away.

The discreet placing of the catheter meant that Jayne, who was very self-aware and loved to 'dress-up' nicely during the day, was able to look 'normal' from the outside and wear her normal clothes. Not bad for a double stoma and PN patient!

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Overall, PN enhanced our lives, we were able to go on holidays - the PN team were incredibly supportive of us doing this and ensured our support and supplies were in the right place for us. We were able to go out to the cinema or even to dinner, though Jayne didn't eat solid foods she could make a plate of it disappear for effect!

The Nutritional Team and PN Nurses were amazing, they could not have been kinder, more patient, or more responsive, and that was just me! Without them we would never have got to grips with this new way of living but it quite literally extended our lives.

My piece of advice to a partner or carer is; ensure YOU learn about every aspect of PN, ensure YOU know what has to be done and what type of feed is given and when. Be confident and show your partner YOU are able to carry out the connection and disconnection for them in case it's needed. Most of all, be involved, meet the people, meet the couriers, meet and talk to the nutrition team; being interested gives confidence. Be patient and caring at all times.

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