



Irish Society for  
**Clinical Nutrition  
& Metabolism**

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Are you a patient or carer of someone receiving either home parenteral or enteral (tube feeding) nutrition living in Ireland?

If so, we want to hear from you.

### Who we are

The Irish Society for Clinical Nutrition and Metabolism (IrSPEN) is a non-profit, voluntary organisation of doctors, dietitians, nurses and other healthcare professionals dedicated to improving nutritional care of patients in Ireland.

### Have Your Say

If you are a patient on nutrition support at home, or care for someone that is, please take just 5 minutes to complete our short survey, designed to find out more about the support needs of home nutrition patients around the country.

### Why we ask

As many IrSPEN members are healthcare professionals who are involved with patients with complex nutritional needs, we want to know how we can help improve the support and information available to patients on long term enteral or parenteral nutrition at home.

### Patient Support Meeting – Spring 2020

In the UK, an organisation called Patients on Intravenous and Nasogastric Therapy (PINNT) provides support and an online forum for patients on home feeding, but in Ireland, no such patient organisation currently exists. With this in mind, IrSPEN, in conjunction with PINNT, is planning to organise a meeting for patients and carers in a central location in Dublin in late spring, where there will be an opportunity to hear from invited speakers on relevant topics and share experiences. Your responses to the survey will help us tailor the programme to meet expectations, while giving us a better idea of the support needs of patients around the country and the interest in having other events and support days.

### How to complete the survey

At the end of the survey, you will be given the option of providing IrSPEN with your contact details so that we can send you further information and joining details for the Spring patient meeting. Your personal information will remain separate from the results of the survey to maintain anonymity and will not be used other than for the purposes stated.

## Survey of Patients / Carers of patients receiving home artificial nutrition support

\* Artificial nutrition support = enteral nutrition (tube feeding) and parenteral nutrition (TPN)

### 1. Which of the following best describes you?

I am a patient receiving nutrition support

I am a carer or family member of the patient receiving artificial nutrition support



### 2. If you are the carer, which best describes your relationship with the patient?

I am a parent/ guardian of the patient

I am a spouse / partner of the patient

I am a sibling of the patient

Not applicable

Other please specify \_\_\_\_\_



### 3. Patient Gender?

### 4. Patient Age (yrs)?

### 5. Which of the following best describes the way you get your nutrition?

Nasogastric (through a tube in my nose that goes into my stomach e.g NG)

Naso jejunal (through a tube in my nose that goes into my bowel e.g NJ)

Gastrostomy (through a tube in my stomach e.g PEG/RIG)

Jejunal (through a tube in my bowel e.g jejunostomy, PEJ, PEG-J)

Parenteral (through a line into a vein in my arm or chest e.g PN/ TPN)



### 6. How long is it since you first started getting nutrition support e.g through a tube or a line in your vein?

0 – 6 months

6 – 12 months

1 – 5 years

5 -- 10 years

10 - 20 years

>20 years



### 7. Which hospital or community service do you attend for monitoring of your nutrition support?

8. Are you currently a member of the UK based charity PINNT?

Yes  No

9. Would you like there to be an organisation for people receiving nutrition support based locally (offering the opportunity to have local meetings/events)?

Yes  No

10. Would you like the opportunity to attend a group meeting organised by healthcare professionals and patients in Ireland?

Yes  No

11. What part of Ireland do you live in?

Leinster   
Munster   
Connaught   
Ulster

12. Preferred city and best time of the day (pick any/all that would work for you)?

Dublin   
Cork   
Limerick   
Galway   
  
Morning   
Afternoon

13. Would you prefer to attend a group meeting in person or online as a webinar?

In person   
Webinar

14. Please let us know of any other special requirements or constraints?

**15. Can you tell us what would interest you most about attending a patient support event or having a local organisation to join or access? Tick as many as you feel relevant to you:**

- Talking/sharing experiences with others on nutrition support?
- Sharing/hearing about how other people cope with their feeding?
- Obtaining practical information (eg. *travelling with feeds, etc*)?
- Finding out what services are available for day to day living locally?
- Hearing experts talk on key topics that may be of interest/ help?
- Having regular updates in relation to your feeding/equipment etc?
- Working with others in a group to seek improved services or support?
- Setting up social events or meetings with others in similar situations?
- Volunteering /taking on an organising role within a group organisation?
- Anything else not listed:

  
  
  
  
  
  
  
  
  

**16. What way would you prefer to communicate with other people and receive information from a support group? (tick as many as apply)**

- Face to Face
- Facebook
- Twitter
- Instagram
- Newsletter
- Website
- Other (please specify) \_\_\_\_\_

  
  
  
  
  
  

**17. Please add any other comments or suggestions:**

**18. If you would like IrSPEN secretary to contact you about its patient support day meeting and to provide an update on its work to help support patients on enteral/parenteral nutrition further, please provide your contact details. (No personal information will be used other than for the purpose of contacting you with information regarding a patient meeting and your information will not be shared)**

Name \_\_\_\_\_

Email Address \_\_\_\_\_

Please scan a copy to [info@irspen.ie](mailto:info@irspen.ie) or by post to Martina Smyth, IrSPEN, Andale, Toberpatrick, Tinahely, Co. Wicklow, Y14 TV20