Introduction
Parenteral nutrition (PN) is a life sustaining therapy that can be confronting for patients and their carers. In 2008, the NSW Agency for Clinical Innovation (ACI) Nutrition and Gastroenterology Networks began developing best practice guidelines for the use of PN in hospitals. Throughout the project, consumer working group members identified the need for a resource specifically for consumers and their carers.

Following the launch of the ACI PN Pocketbook the Networks approached relevant consumer groups to develop a patient and carer resource. With their endorsement, a working group consisting of consumer group representatives and clinical experts was formed. Chaired by a consumer, the group created a pamphlet that provides introductory information for patients who are about to commence PN and their carers.

Purpose
The primary purpose of this project is to evaluate the draft pamphlet Parenteral Nutrition: An Information Guide for Patients and Carers (Appendix 1). The pamphlet aims to provide some introductory information on PN and encourage patients and carers to communicate openly with staff, to ask questions and to participate actively in their care. As such, we were interested in the views and experiences of patients, carers and clinicians from across NSW.

The results will be used to assess whether the pamphlet meets its objective and whether it requires any changes prior to being made more widely available.

Methods
The pilot was conducted within 4 NSW public hospitals (Prince of Wales Hospital, Dubbo Base Hospital, Bankstown Hospital and Sydney Children’s Hospital Network – Westmead Campus), in a staged approach between July 2012 and April 2013. The South Eastern Sydney Local Health District Human Research Ethics Committee – Northern Sector provided ethical approval as a Low or Negligible Risk project. There were 2 participant groups – patients commencing PN and their carers; and clinicians using the PN information guide to educate patients on PN.

All patients who commence PN within the study period were eligible to participate. Patients were identified by principal investigators (clinicians) as part of usual care (ie referral for PN). The study was conducted in two groups:
- Control group (or the “No pamphlet” group) received standard care and were asked questions via a written survey about the information provided to them about PN therapy. Participants in the control group received a copy of the pamphlet after completing the survey.
- The “Pamphlet group” (standard care plus the PN pamphlet) were asked the same questions and asked to comment on the pamphlet itself.

The study was explained to participants and consent was obtained by the principal investigators.

All clinicians who educate patients using the PN pamphlet were eligible to participate and were asked to complete a multiple choice survey.

See Appendix 2 for the surveys used in the pilot.
Summary of Results (see Appendix 3 for more details)

- 4 sites participated in the pilot – Prince of Wales Hospital, Sydney Children’s Hospital network – Westmead Campus, Bankstown Hospital and Dubbo Base Hospital.
- A total of 44 patients/carers and 4 clinicians completed surveys.

<table>
<thead>
<tr>
<th>Patients / carers</th>
<th>No Pamphlet</th>
<th>Pamphlet</th>
<th>TOTAL</th>
<th>Excluded</th>
<th>Clinicians</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prince of Wales Hospital</td>
<td>8</td>
<td>10</td>
<td>18</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Sydney Children’s Hospital Network – Westmead</td>
<td>4</td>
<td>3</td>
<td>7</td>
<td>19</td>
<td>1</td>
</tr>
<tr>
<td>Bankstown Hospital</td>
<td>3</td>
<td>3</td>
<td>6</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Dubbo Base Hospital</td>
<td>9</td>
<td>4</td>
<td>13</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>TOTAL</td>
<td>24</td>
<td>20</td>
<td>44</td>
<td>24</td>
<td>4</td>
</tr>
</tbody>
</table>

Reasons for exclusion were reported from 2 sites
- SCHN
  - Parents non-English speaking and no interpreter available x 2
  - Neonates x 14
  - Paediatric ICU admissions from Oncology x 2
  - Bone Marrow Transplant – within a few days of transplant in isolation x 1
- Bankstown
  - One passed away the next day.
  - One too unwell and very confused + no family around (now deceased)
  - One too unwell and PN only in for a day or so then he went to Theatre several times and end up having NJ instead of PN
  - One too unwell and been bouncing back and forth between Bankstown and Liverpool Hospitals
  - One was sedated + intubated in ICU with no family around.

Discussion / Conclusions

• The resource was generally well received by patients who were able to provide feedback – they were positive about the amount of information and readability. It was effective in helping patients and carers understand PN.
• Clinicians felt it was a useful resource for patients starting PN; however they also noted that these patients are usually very unwell, and the patients and their carers are often overwhelmed by medical procedures and information. They felt a number of changes were required to make it more user friendly (such as larger font size and simplifying content).
• The pilot provided the opportunity to gain valuable feedback from patients, carers and clinicians that will be used to further improve the PN Pamphlet.
• The opportunity to work together on this project led to important insights for both clinicians and consumers.

Recommendations

• After reviewing the results of the pilot, the working group recommended a number of changes to the pamphlet, including
  • Changing the format to a 2 sided “factsheet” and increasing the font size. To achieve this, the content needed some revision to reduce the word count.
  • Removing duplication and complex terms.
  • Using shorter sentences and words with fewer syllables where possible to improve readability.
• See Appendix 4 for the new PN factsheet which will be uploaded to the ACI website and translated into different languages.
• Both consumers and clinicians should be involved in the development of education resources for consumers and it is beneficial to use a variety of methods to gain their input. This helps ensure there is a balance between clinical content and consumer comprehension for resources to have the maximum effect.
Acknowledgements
Karen Winterbourn  Parenteral Nutrition Down-Under
Kathy Stewart  IBD Support Australia Incorporated
Suzie Daniells  Prince of Wales Hospital
Mark Sutherland  Prince of Wales Hospital
Karen Rankin  Sydney Children’s Hospital Network – Westmead Campus
Katie Marks  Sydney Children’s Hospital Network – Westmead Campus
Subhacha Ganyamas  Bankstown Hospital
Kirstine Metcalfe  Dubbo Base Hospital
Katherina Angstmann  Royal North Shore Hospital
Lynn Hyde-Jones  Royal Prince Alfred Hospital
Ellen Rawstron  Agency for Clinical Innovation

Contacts
Tanya Hazlewood – Network Manager, Nutrition
Agency for Clinical Innovation
Tanya.hazlewood@aci.health.nsw.gov.au  (02) 9464 4635  0417 453 215

Kirsten Campbell – Network Manager, Gastroenterology
Agency for Clinical Innovation
Kirsten.campbell@aci.health.nsw.gov.au  (02) 9464 4622  0431 091 113
APPENDIX 1 – The Original PN Pamphlet

Frequently Asked Questions

What can happen if I stop PN treatment? Stopping PN treatment too soon can lead to deficiencies in nutrients, which may result in malnutrition. It is important to continue PN therapy until your body is able to manage other sources of nutrition effectively.

Can I eat normal food and PN at the same time? Yes, you can eat normal food and PN simultaneously to provide both a balanced diet and a regular source of nutrients.

Can I continue on PN therapy at home? Yes, you can continue PN therapy at home with the appropriate equipment and supervision. However, it is important to follow all the precautions and guidelines provided by your healthcare team.

How often must I have my PN therapy? The frequency of PN therapy depends on your medical condition and the type of therapy. Typically, PN is administered at least 2 to 3 times a week.

Glossary of Terms

Parenteral Nutrition

PN, Parenteral Nutrition: A method of delivering nutrients into the bloodstream directly into a vein or a major large artery, bypassing the digestive tract. This is commonly used in patients who are unable to consume food or who have severe malnutrition.

PN Solution

PN solution: A mixture of nutrients, including carbohydrates, proteins, lipids, vitamins, and minerals, that is infused into a vein or artery to provide the necessary nutrients for the body.

PN Catheter

PN Catheter: A thin tube inserted into a vein or artery to deliver the PN solution directly into the bloodstream.

PN Infusion

PN Infusion: The process of delivering the PN solution into the bloodstream through a catheter or a peripheral line.

Parenteral Nutrition

Parenteral Nutrition: The administration of nutrients directly into the bloodstream through a catheter or a peripheral line, bypassing the digestive tract.

How does it work?

Intravenous Micronutrients

Intravenous Micronutrients: Nutrients that are added to the PN solution to provide a balanced diet of essential nutrients for the body.

Advantages of PN

Advantages of PN: The benefits of PN therapy include rapid delivery of nutrients, reduced risk of malnutrition, and improved quality of life. However, it is essential to monitor the patient closely and adjust the PN therapy as needed.

Parenteral Nutrition

An Information Guide for Patients and Carers

This pamphlet was developed by the ACI Gastroenterological and Nutrition Networks, the Parenteral Nutrition Network, the NSW Agency for Clinical Innovation, and IBD Support Australia Inc.
APPENDIX 2 – The surveys

PARENTERAL NUTRITION INFORMATION EVALUATION – PATIENTS AND CARERS

Thank you for taking the time to participate in this survey. The purpose of this survey is to find out patient and carer views on the information available regarding parenteral nutrition (PN) in hospitals and in particular, the draft pamphlet Parenteral Nutrition: An Information Guide for Patients and Carers. This multiple choice questionnaire will only take a few minutes to complete.

All surveys will be kept confidential and the results will be collated into a report for the Agency for Clinical Innovation (ACI). No hospital or individual will be identified in this data. Therefore, you do not need to put your name on the survey.

When you have completed the survey, please enclose it in the self addressed envelope that was provided to you and return it to the staff member who spoke with you regarding this project and survey.

If you have any questions at any stage, please speak with the staff member who provided the information to you.

<table>
<thead>
<tr>
<th>QUESTION</th>
<th>ANSWER</th>
<th>COMMENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am the...</td>
<td>□ Patient receiving PN</td>
<td>□ Parent of a child receiving PN</td>
</tr>
<tr>
<td>What is the age of the person receiving PN?</td>
<td>□ 0-5 years</td>
<td>□ 5-10 years</td>
</tr>
<tr>
<td>Is English the main language spoken at home?</td>
<td>□ Yes</td>
<td>□ No</td>
</tr>
<tr>
<td>Who gave you information about PN?</td>
<td>□ Doctor</td>
<td>□ Nurse</td>
</tr>
</tbody>
</table>

PN Consumer Information Pamphlet project – Survey 1: Patients/Careers – Pamphlet Questionnaire – v1.0
**PARENTERAL NUTRITION INFORMATION EVALUATION – PATIENTS AND CARERS**

Thank you for taking the time to participate in this survey. The purpose of this survey is to find out patient and carer views on the information available regarding parenteral nutrition (PN) in hospitals.

This multiple choice survey will only take a few minutes to complete.

All surveys will be kept confidential and the results will be collated into a report for the Agency for Clinical Innovation (ACI). No hospital or individual will be identified in the data. Therefore, you do not need to put your name on the survey.

When you have completed the survey, please enclose it in the self-addressed envelope that was provided to you and return it to the staff member who spoke with you regarding this project and survey.

If you have any questions at any stage, please speak with the staff member who provided the information to you.

<table>
<thead>
<tr>
<th>QUESTION</th>
<th>ANSWER</th>
<th>COMMENTS</th>
</tr>
</thead>
</table>
| I am the... | □ Patient receiving PN  
□ Parent of a child receiving PN  
□ Family member/carer of a patient receiving PN  
□ Other |          |

What is the age of the person receiving PN?
| □ 0-1 years  
□ 1-5 years  
□ 5-10 years  
□ 10-15 years  
□ 15-24 years  
□ 25-64 years  
□ > 65 years |          |

Is English the main language spoken at home?
| □ Yes  
□ No |          |

---

*PN Consumer Information: Pamphlet project – Survey 2: Patients/Carers – Non-Pamphlet Questionnaire – v1.0*

---

**Who gave you information about parenteral nutrition?**

(please tick all that apply)

| □ Doctor  
□ Nurse  
□ Dietitian  
□ Other  
□ I didn’t receive any information |          |

**How easy was the information to understand?**

(please tick)

| □ Very easy to understand  
□ Easy to understand  
□ Difficult to understand  
□ Very difficult to understand  
□ I’m not sure |          |

**How well did the information help you understand PN?**

| □ Very well  
□ Well  
□ Not at all  
□ I’m not sure |          |

**How much information did you receive?**

| □ Too much  
□ Just the right amount  
□ Not enough  
□ I’m not sure |          |

**Is there any other information you think needs to be provided?**

<Free text>

---

Thank you for taking the time to complete this survey.

Please use the self-addressed envelope and return the survey to the staff member who spoke with you regarding this project and survey.
**PARENTERAL NUTRITION INFORMATION EVALUATION – CLINICIANS**

Thank you for taking the time to participate in this survey. The purpose of this survey is to obtain feedback from clinicians on the parenteral Nutrition: An information guide for patients and caregivers.

This is a multiple choice survey and will only take a few minutes to complete.

All surveys will be kept confidential and the results will be collated into a report for the Agency for Clinical Innovation (ACI). No hospital or individual will be identified in the data. Therefore, you do not need to put your name on the survey.

When you have completed the survey, please place it in the self-addressed envelope that was provided to you and return it to the staff member who spoke with you regarding this project and survey.

If you have any queries at any stage, please speak with the staff member who provided the information to you.

<table>
<thead>
<tr>
<th>QUESTION</th>
<th>ANSWER</th>
<th>COMMENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am a:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurse, Level (e.g. CNS, CNC)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doctor</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| Approximately how many patients/careers did you provide the pamphlet to? | | |
|---|---|
| 0-10 | | |
| 11-15 | | |
| >15 | | |

<table>
<thead>
<tr>
<th>For all patients/careers, the information in the pamphlet was</th>
<th>Too complex</th>
<th>Just right</th>
<th>Too simple</th>
<th>Not sure</th>
</tr>
</thead>
</table>

Please turn over for page 2 questions.

---

For my patients and caregivers, the amount of information in the pamphlet was:
- [ ] Too much
- [ ] Just right
- [ ] Too little
- [ ] Not sure

Did the pamphlet encourage your patients and caregivers to ask questions and discuss PN with you?
- [ ] Yes
- [ ] No
- [ ] I’m not sure

Overall, do you feel that this pamphlet has helped your patients and caregivers understand PN therapy?
- [ ] Yes
- [ ] No
- [ ] I’m not sure

Will you continue to use the pamphlet?
- [ ] Yes
- [ ] No
- [ ] I’m not sure

If yes or no, why?

Is there any way you think we should improve or change the pamphlet?
- [ ] Yes
- [ ] No
- [ ] I’m not sure

If so, please provide details:

Thank you for taking the time to complete this survey.

Please use the self-addressed envelope and return the survey to the staff member who spoke with you regarding this project and survey.
APPENDIX 3 – Results

Part A – Patients / Carers

Comments
- Family – Patient can’t handle any of this (ie filling in the survey)

Comments
- “hard to see your child with the PICC line because of pain and risk of infections and I am worried about the side effects of this”
Comments
Languages
- Arabic x 2
- Urdu x 1
- Spanish x 1
- Samoan (and english) x 1

Who gave you the information about Parenteral Nutrition?

Comments
- very helpful, explained excellently (Dietitian)
- Although the Dr and Dietitian gave me information I was not aware that I was receiving “PN”.
- Dietitian explained method and reason for PN. Doctor explained method of inserting PICC
- 1 x pt had PN in the past
ACI Nutrition and Gastroenterology Networks

Comments
- I am also a medical person (“easy”)
- I understood all the information I was given.

Comments
- nil
Comments
- But as a nurse, I had existing knowledge of this (“just the right amount”)

Comments
- I suspect the level of comprehension will be related to the education level of the patient. Could be tricky for persons lacking in basic education/language skills.
- Very easy – I am a nurse so know about TPN
- Difficult to read – print too small
- Small writing
- I’m too unwell (“I’m not sure”)
- Too small (“very difficult”)
Will you use the information provided in the pamphlet? (n=20)

- Yes: 80%
- No: 20%

**Comments**

- Yes
  - For care and hygiene
  - To increase my own knowledge of PN and to explain to family/friends why I am receiving this treatment.
  - If in hospital I will ask for it.
  - To explain to my mother why I need PN.
  - To inform family and friends
  - Pass on info provided under FAQ section
  - Read and use what I need to
  - Follow-up guidelines provided

- No
  - I already know (nurse).
  - Don’t need PN any more
  - No information re clot. Pt had blood clot in PICC line.

**Is there any other information you think needs to be provided?**

- Mention it takes time to come off PN
- It’s done gradually when intro fluids then food
- Side effects of short and long term PN
- No - very happy
- What are the risks?
- When you stop treatment it would be nice to know why you need as if you don’t know feel why you are not feeling hungry
- No other info requested, patient had a basic understanding only
- Difficult to understand in the environment, too many people and i wasn't well
- Perhaps more info regarding what i was actually getting
- I didn't receive much info, but it was enough for me to know what was going on, i dind't need great detail.
- Would have liked more information to understand
- Happy with care provided
- Too complicated - not very well at the moment, can't absorb the info.
Part B – Clinicians

- 4 Dietitians completed the survey
  - 1 provided the pamphlet to 10-15 patients/carers, 1 to 5-10 patients/carers and 2 to <5 patients/carers
  - 1 thought the pamphlet was too complex for their patients, 3 thought it was “just right”
  - All 4 thought the amount of information was “just right”
  - 2 reported that the pamphlet did not encouraged patients/carers to ask questions and discuss PN, the other 2 did.
  - 3 felt that the pamphlet had helped their patients/carers understand PN, the other was “not sure”
  - 2 said they would continue to use the pamphlet, 2 were “not sure”
  - 2 felt there should be changes made to the pamphlet

Comments

- Positive
  - Very useful for those on long term PN
  - Was very useful – patients could read at their own leisure then ask questions later.
  - Overall it was easy to use, fairly simple to understand and most of the parents really appreciated someone going through the information with them

- Comments about content / use and changes required
  - Font size too small
  - Font much too small and wordy; bullet points would be preferable to aid education
  - The amount of info was just right for many, too much for some
  - Those unwell or on short-term PN were less interested
  - I had one client (surveyed) who was from a non-English speaking background (though did say in survey that English 1st language) that I feel was too complex for.
  - Most non-pamphlet patients surveyed said they received ‘the right amount of information’... I feel perhaps they just don’t know what they don’t know.
  - It seems like a good supplement to leave with the patient but I hated using it for education - it’s too complex for basic education
  - Needs more FAQ - how long will it likely last, what happens when it’s weaned, why do I need insulin, why do they take my blood every day?

- Other comments
  - Patients asked questions when giving verbal education, before they read the pamphlet
  - I had no questions from patients after using the pamphlet
  - Many patients seemed just too sick to want to read
APPENDIX 4 – The New PN Factsheet

Parenteral Nutrition
An Information Guide for Patients and Carers

You have been referred for Parenteral Nutrition (PN). This factsheet will help you to understand what this is and how it may affect you.

What is Parenteral Nutrition (PN) and why is it needed?
When you eat, food passes from the stomach into the digestive tract (also known as the bowel) or gut, where it is broken down and absorbed into the body. However, you may not be able to absorb food in the normal way. There might be various reasons for this and you can discuss this with your medical team.

When your digestive tract is not working, you still need nutrition. This is when you need PN (sometimes called Total Parenteral Nutrition or TPN). PN is a sterile solution containing nutrients normally found in food – proteins, carbohydrates, fat, water, vitamins, minerals and electrolytes.

The solution is infused straight into the bloodstream, bypassing the digestive tract.

You will need PN until the digestive tract is working properly (absorbing nutrients). Just like eating and drinking after any illness, improving your nutritional state takes time. This may include slow weight gain, if required.

How does it work?
PN is given via a very thin intravenous (IV) line that is inserted into a large vein in the arm. Usually, the nursing staff will check the site on the arm or leg.

You will be prescribed the type of glucose (sugar) and fluid that is best suited to you as well as any medications.

Frequently Asked Questions

Will I feel hungry or thirsty?
On PN, you may not feel hungry or thirsty at all. This is because you are receiving all the nutrition you need. If you are feeling hungry or thirsty, talk to your medical team.

Can I eat and drink?
This depends on your medical condition. This will be explained by your medical team.

Oral hygiene/mouth care
Good mouth care is important even when you’re not eating or drinking. If your mouth is dry, tell your medical team.

Will I still need to go to the toilet?
Yes. Your bladder should work normally. The bowel still produces stools. If you are not eating.

What happens if my dressing is loose or coming off?
The catheter site must remain clean and dry, If the dressing is wet, loose or soiled, tell your nurse immediately.

Can I shower?
Yes. Your catheter site and dressing must be kept dry to the shower. Baths are recommended for children. If your catheter site or dressing becomes wet, tell your nurse immediately.

Benefits and risks
This medical team will discuss the benefits and potential risks of PN with you.

If you have any other questions please speak to a member of your medical team.

The picture below are two examples of how PN can be given via a "central" line. It could be called a "PICC" line (a peripherally inserted central catheter).

PN is usually infused continuously over 24 hours. The infusion rate changes throughout the same time frame.

What will happen while on PN?
During your therapy you will require monitors.

You will include regular blood tests, serum tests, pulse and weight checks. Nursing staff will care for your therapy and urine tests.

It is very important to keep the catheter clean.

Glossary of Terms
Catheter (intravenous) a tube that can be inserted into a vein to give medications or fluids straight into the bloodstream.

Digestive tract (gastrointestinal tract) the organs that break down food and absorb the nutrients that are used by the body. For food. The organs of the digestive tract are the mouth, esophagus, stomach, small and large bowel (intestine), rectum and anus.

Intravenous Infusion a method of giving drugs and fluids continuously, through a needle or catheter, inserted into a vein.

This information sheet was developed by the ACI Nutrition and Gastroenterology Network. It can be downloaded from the ACI Nutrition and Gastroenterology Network website.