NNG News

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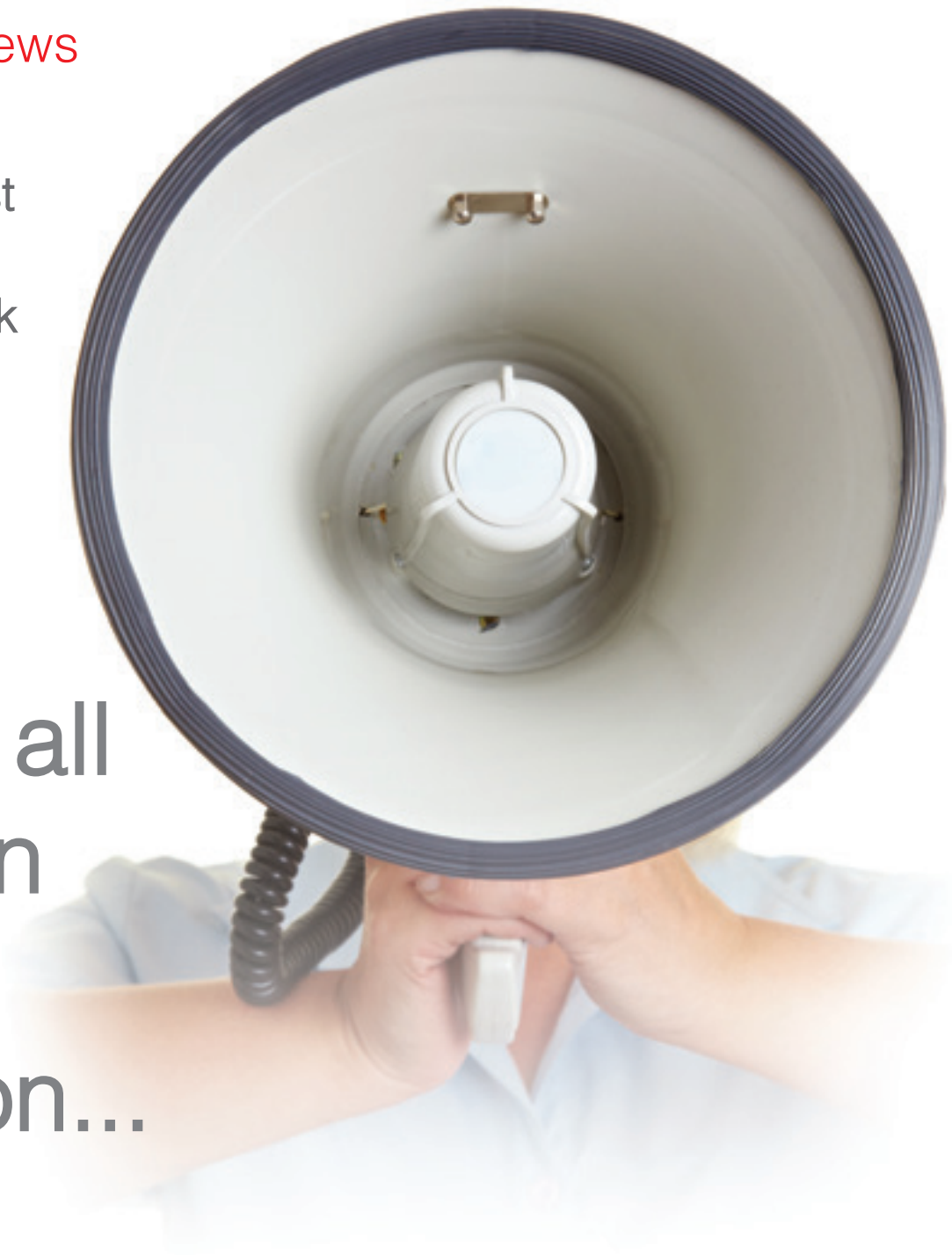

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Chair's Welcome

Liz Evans
RGN, Dip HE (Nursing) BA (Hons) Nursing Practice

Whose choice is it anyway?

As nurses we are taught about the patient being at the heart of what we do. Indeed, Government policy insists that patient choice is paramount in delivering good care. The Department of Health published a document in February 2012 – the NHS Patient Experience Framework. This framework listed eight key elements which state what is important to patients.

First on the list is: **"Respect for patient-centred values, preferences, and expressed needs,** *including: cultural issues; the dignity, privacy and independence of patients and service users; an awareness of quality-of-life issues; and shared decision making."*

Honouring the content of this statement should be at the centre of all our work with patients, particularly if we consider patients who are being discharged home with parenteral nutrition (PN). Not only are they expected to cope with the massive life changing event of managing all their fluid and nutritional needs via a central line, they are expected to take on the responsibility for caring for their line and setting up feeds independently, in addition to recovering from illness.

So, shouldn't we want to make life as easy as possible for them?

Shouldn't we want them to be able to make an informed choice as to what pump is best for them? After all, it is their body, their home, their life so should they not be involved in making the decision as to what best suits them?

In 2011, a standing committee of Patients on Intravenous and Nasogastric Nutrition Therapy (PINNT), LITRE (Looking Into the Requirement for Equipment), produced a report looking at the various pumps available on the market for HPN patients (see next page for Carolyn Wheatley's article).

It is somewhat worrying, however, that according to PINNT many patients are not being given this choice. They are given conflicting information by hospitals and homecare companies. This is simply not fair on the patient. Logic would dictate that it should be the discharging hospital who provides the patient with the initial information and pump choice.

I am sure that Carolyn would agree when I say that a person who has just been discharged from hospital is extremely anxious and vulnerable, and wants to do the right thing. They will, therefore, in some instances, do whatever is perceived best by the care givers. This is wrong. They should be given an informed choice and the chance perhaps to try several pumps until they find the one they like. After all – this pump is their lifeline and it has to be the right one.

Should we as nurses be entering into a dialogue with our patients to determine how they want to live their life? Is their goal, within the parameters of their condition and treatment, that they should have freedom within the boundaries? Do nurses fully understand the limitations and restrictions of some of these pumps? We know they 'deliver' feed but how is a question we should ask or investigate.

I completely agree with the comments made by Mia Small and Simon Gabe. Patient care, safety and quality should be the driving force here. In this instance, cost should not be the prime consideration.

Let us take the words of the NHS Patient Experience Framework and apply them here. This is all vital to the health and wellbeing of our patients. They deserve nothing less.

Reference: Department of Health (2012). The NHS Patient Experience Framework. Available at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_132786

Calling all Nutrition Nurses to Action…

Carolyn Wheatley
Chair, PINNT, cwheatley@pinnt.com – www.pinnt.co.uk

PINNT

Do you have home parenteral nutrition (HPN) patients under your care? If you do then who makes the decision about what pump they use at home? Is it you, the homecare provider, or is it a joint decision between you and the patient? What basis is used to make the decision?

PINNT, the patients support group, have been actively campaigning for a number of years through the work of LITRE (Looking into the Requirements for Equipment) to encourage decision makers to consider the patient's lifestyle choice and personal needs in any decisions made. To the patient, the pump and accessories can be so much more than a piece of equipment that delivers their feed.

LITRE published a user perspective review of the ambulatory pumps that were available on the market during May 2011, and published their findings in August 2011. You can read the full report on PINNT's website: www.pinnt.co.uk

Following this report PINNT received numerous comments from their members saying that they were told they had to have a certain pump

because *'the homecare providers said so'* but on raising the issue with the homecare providers PINNT were told that ***'it's was not their decision, it's the referring unit who decides'***. Neither response is particularly helpful. In an attempt to try and bring clarity to this situation PINNT contacted two healthcare professionals who were both patient focused and aware of the work of PINNT and LITRE, Mia Small and Simon Gabe.

The LITRE report was published in Complete Nutrition in February/March 2012 and a foreword co-written by **Mia Small**, Consultant Nurse, Lennard Jones Intestinal Failure Unit, and **Simon Gabe**, Consultant Gastroenterologist & Hon. Senior Lecturer, Co-Chair of the Lennard Jones Intestinal Failure Unit at St Mark's Hospital, accompanied the report. The foreword stated:

"This report by LITRE is unique in many respects. It is a comprehensive review of ambulatory pumps for long term parenteral nutrition. It is clear and informative for patients, carers and other healthcare professionals.

Choosing a pump is a key decision that is often underestimated. However, correctly choosing the right pump, which best fits a patient's lifestyle, can help to ease the burden of managing life on parenteral nutrition. Most centres will have a limited experience of ambulatory pumps and will often tell patients "this is the pump that we use". It is easy to assume that one pump will meet all patients' requirements, but this is not the case. By having this clear, concise information we can all be more informed. Any healthcare professional who has read this document will inevitably stop and think that little bit more about their patient. Any patient reading this document can feel reassured that there is collaboration between industry, healthcare professionals and themselves.

You may be forgiven for thinking that this report is all about the pumps. However, the pump is just one element. Readers are prompted to consider the ancillaries which are equally important. If the spike on a giving set is difficult to insert or the giving set is hard to prime then the consequences may not just affect quality of life but also may result in complications such as infection or occlusion.

This report does not include the cost of the pumps or ancillaries. This is correct as it is important to choose the right pump for the patient based on lifestyle issues and the patient's abilities. This document will help centres justify their pump choice to commissioners.

The publication of this abridged version of the LITRE Report Looking Into The Requirements for Equipment (published in August 2011) in Complete Nutrition raises its importance to healthcare professionals, and makes it more accessible. It will be an invaluable resource for new or developing intestinal failure units as well as large units such as St Mark's."

Calling all Nutrition Nurses to Action - continued

As we move forward into a new HPN framework we need to ensure that the right people are making the decision regarding what pump is appropriate, on an individual basis, and if the first choice does not provide an acceptable quality of life for the patient that they are open to discussing options that that are more suitable, which may mean that another option should be sought.

As **Liz Evans**, Chair of the NNNG, highlights:

"When considering pumps a few key aspects need to be considered, including internal battery life and charging time, ease of programming, and whether the pump has an external battery.

I would urge every healthcare professional who is involved in the care of HPN patients to read this document by LITRE. I would then advise them to hand the document to their patients to read when starting to think about discharge planning. That way you are assisting the patient to be involved in the decision making process and see what equipment is available.

Once at home, I would also suggest that the pump is reviewed regularly with the patient to ensure that they are happy with it and it fulfils their needs. Just because they are discharged with one pump does not mean that it remains the best option one year later. Also remember to consider associated issues, such as problems with the giving set – it may be difficult to prime or spike the bag.

We should also bear in mind that their lifestyle may have changed since commencing HPN; for better or for worse!"

If you are involved in making decisions regarding pumps for HPN patients please bear in mind the thoughts put forward by Mia Small and Simon Gabe – your choice about the pump should not come at a premium.

Reference: LITRE (2012). LITRE Assessment of Ambulatory Pumps for Parenteral Nutrition – Results of a LITRE Assessment Panel. Complete Nutrition (2012); 12(1): 13-16.

Enteral Nutrition Nurse Specialist Recognised for Pioneering Work

Linda Warriner, Enteral Nutrition Nurse Specialist for County Durham and Darlington NHS Foundation Trust, is heading 'down under' to study in Australia after being awarded the 'Florence Nightingale Foundation Travel Scholarship 2012-13.

Linda will be using her funding award for a study in the UK and Australia which will compare the service provision and guideline development for enteral feeding.

"I strongly believe that good quality care should be provided for all our patients and that this is underpinned by robust policies guidelines and protocols that are evidence based. Achieving the scholarship was a challenging process and involved preparing submissions and attending an interview at the Florence Nightingale Foundation's offices in London. I was amazed but delighted to be accepted. It's fantastic; I can't wait to find out what they are doing out in Australia," stated Linda.

Linda is a pioneer in the field of enteral feeding. She sits on the NNNG Committee and has been instrumental in the developing, reviewing and implementing guidelines to bring consistency and improved standards to the delivery of care at a national and local level.

Linda continued: *"I feel that being currently involved in national discussions, in addition to the work I'll undertake as part of the scholarship, will benefit patients immensely. I am constantly striving to identify improvements or areas where we could be delivering better care and finding solutions to be able to achieve this.*

I am passionate about sharing knowledge and experience with other healthcare professionals, and feel this study will provide an opportunity to have a more global view of service provision. The sharing of knowledge and experience gained within the study could influence service delivery locally and nationally, whilst offering more choices, treatment options and services to the patient that may hopefully improve the patient's quality of life."

Linda flew to Australia in April (2013), and during her month stay will visit Sydney, Melbourne and Brisbane. Linda has made arrangements to spend time with a number of organisations and healthcare professionals, including the Australian Agency for Clinical Innovation, Enable New South Wales, the Alfred Hospital in Melbourne, the Westmead Hospital Sydney, and community placements in the surrounding areas and Brisbaine.

Linda will be regaling us with her adventures when she presents her experiences in Australia at the NNNG Conference later this year.

Following on from the scholarship Award, Linda has been invited to attend the Girdlers Presentation to be awarded the Girdlers Medallion for her work leading up to the scholarship. The Girdlers are a company that supports many different charities and give millions away each year. This year they have chosen to support Linda as they felt her project was the most innovative and recognised all the hard work she had undertaken in preparation for her scholarship.

To add the cherry on the cake Linda has also been shortlisted by the BJN for Community Nurse of the Year Award.

Abstract Reviews

Very Low Birth Weight Preterm Infants are at Risk for Hypoglycaemia once on Total Enteral Nutrition

Staffler A, at el. J Matern Fetal Neonatal Med. 2013 Mar 26. [Epub ahead of print].

OBJECTIVE: To determine the occurrence of hypoglycaemic episodes in very low birth weight preterm infants under total enteral nutrition and identify potential risk factors.

METHODS: In this single centre cohort study, we analysed the patients' charts of preterm infants with a gestational age <32 weeks (n=98). Infants were analysed in two groups (group 1: birth weight <1000g, n=54; group 2: birth weight 1000-1499g, n=44). A total of 3640 pre-feeding blood glucose measurements were screened. Risk factors for the development of hypoglycaemia were identified by linear and multiple logistic regression analyses.

RESULTS: In group 1, 44% (24 of 54) of infants experienced at least one asymptomatic episode of blood glucose <45mg/dl (<2,5mmol/L) as compared to 23% (10 of 44) in group 2. Regression analysis identified low gestational age and high carbohydrate intake as potential risk factors for the development of hypoglycemia.

CONCLUSIONS: Our results indicate that numerous preterm infants experience hypoglycaemic episodes once on total enteral nutrition, especially those who are <1000g at birth and those with a higher carbohydrate intake. Further studies evaluating a possible impact of these common though asymptomatic episodes on later development could help to better define thresholds that should be considered as 'hypoglycaemia' in this population.

Comparison of Two Types of Surgical Gastrostomies, Open and Laparoscopic in Home Enteral Nutrition

Tous Romero MC, et al. Nutr Hosp. 2012 Jul-Aug; 27(4): 1304-8. doi: 10.3305/nh.2012.27 .4.5860.

AIM: Exposing the complications of surgical gastrostomies used as way of home enteral nutritional support (HEN) and detecting the differences between the two techniques used in our environment: Open Surgery *vs* Laparoscopic Surgery.

MATERIAL AND METHODS: Retrospective descriptive observational study of the surgical gastrostomies performed between 1994 and 2009 followed up by our unit. Have been analysed the complications detected in our practice during the follow-up of patients with HEN performed via open laparotomy vs. laparoscopic techniques, assessing: leaks of gastric fluid to the exterior, abdominal wall irritation, presence of exudate, presence of exudate with positive culture that required antibiotical treatment, burning or loss of substance of the periostomic zone, breach of balloon, decubitus ulcer caused by the tube and formation of granuloma.

RESULTS: Between 1994 and 2009, 57 surgical gastrostomies were performed: 47 using the conventional laparotomic (open) tecnique and 10 laparoscopies. The average age of the patients was 57.51 ± 17.29 years old. The most common cause for the performance of surgical gastrostomy was esophageal cancer (38.6%) followed by neurologic alterations (26.3%) and head and neck tumors (26.3%). 97.9% of the patients who underwent to surgical gastrostomy presented at least one complication, meaning that only 2.1% were free of complications; meanwhile, 50% of the patients were laparoscopic gastrostomy was performed had none of these complications.The most common complications were the presence of leaks of gastric fluid and abdominal wall irritation that appeared on 89.4% and 83% respectively of the laparotomic gastrostomies versus the presence of only 30% of both complications in laparoscopic gastrostomies being the difference statistically significant (p <0.01).

CONCLUSIONS: After the introduction of the laparoscopic technique in the performance of surgical gastrostomies has been observed a decrease of the complications occured during the home enteral nutritional support related to surgical gastrostomies.

Early Enteral Nutrition is Superior to Delayed Enteral Nutrition for the Prevention of Infected Necrosis and Mortality in Acute Pancreatitis

Wereszczynska-Siemiatkowska U, et al. Pancreas. 2013 Mar 15. [Epub ahead of print].

OBJECTIVE: The exact time of initiation of total enteral nutrition (TEN) in severe acute pancreatitis (SAP) and its influence on the disease outcome are not well known.

METHODS: An analysis of 197 cases with predicted SAP allocated to: group A (n = 97), early TEN (started within the first 48 hours after admission to hospital); and group B (n = 100), delayed TEN (started after 48 hours).

RESULTS: Infection of necrosis/fluid collections occurred in 4 patients in group A and 18 patients in group B ($P < 0.05$). Respiratory failure and transfer to intensive care unit occurred more frequently in group B than in group A (15 vs 5 and 15 vs 3 patients; $P < 0.05$). Multiple-organ failure was observed in 9 patients in group A and 16 patients in group B ($P > 0.05$). Seven patients in group A and 11 patients in group B underwent surgery ($P > 0.05$). All 9 reported deaths occurred in group B ($P < 0.05$). The time to start TEN was a predictor of infected necrosis/fluid collection (odds ratio, 4.09; $P = 0.028$).

CONCLUSIONS: Delayed compared to early TEN is associated with higher mortality, increased frequency of infected necrosis/fluid collections, respiratory failure, and a need for intensive care unit hospitalization. Enteral nutrition in SAP should be started within 48 hours after admission to hospital.

The Safety and Efficacy of Parenteral Nutrition among Paediatric Patients with Burn Injuries

Dylewksi ML, et al. Pediatr Crit Care Med. 2013 Mar; 14(3): e120-5. doi: 10.1097/PCC.0b013 e3182712b2b.

OBJECTIVE: Although enteral nutrition is the ideal mode of nutritional support following burn injury, it is often interrupted during episodes of severe sepsis and hemodynamic instability, leading to significant energy and protein deficits. Parenteral nutrition is not commonly used in burn centers due to concerns that it will lead to hyperglycaemia, infection, and increased mortality. However, parenteral nutrition is often utilized in our burn unit when goal rate enteral nutrition is not feasible. To determine the safety and efficacy of a standardized protein-sparing parenteral nutrition protocol in which glucose infusion is limited to 5-7 mg/kg/hour.

DESIGN: Retrospective observational study.

SETTING: Paediatric burn hospital.

PATIENTS: A retrospective medical record review of all children admitted to our hospital with burns ≥ 30% total body surface area was conducted. Only patients admitted within one week of injury and who survived > 24 hours after admission were included in this study.

INTERVENTIONS: None.

MEASUREMENTS AND MAIN RESULTS: A retrospective medical record review of all children admitted to our hospital with burns ≥ 30% total body surface area was conducted. Only patients admitted within one week of injury and who survived > 24 hours after admission were included in this study.

CONCLUSIONS: Judicious use of parenteral nutrition is a safe and effective means of nutritional support when goal enteral nutrition cannot be achieved. A hypocaloric, high-nitrogen parenteral nutrition solution can reduce energy and protein deficits while minimizing complications commonly associated with parenteral nutrition usage.

NNNG Chair Meets the Chairs of the RCN Forums

Liz Evans
NNNG Chair

National Nurses Nutrition Group
Registered Charity No: 295411

Over the past couple of years I have been asked by a number of members what the RCN's stance on nutrition is. I'm sure we can all remember the publicity regarding the release of the RCN Nutrition Now Campaign back in 2007. However since then, the RCN has been (on the whole) curiously quiet.

Earlier this year I approached the RCN to clarify their position on nutrition, and was surprised to be told that they do not have a national nutrition lead. They do have member led professional forums which individually decide on the initiatives regarding nutrition that they feel are important to their forum members.

I discussed the issue with the RCN Director of Nursing and asked how I could engage with these groups. As Chair of the NNNG, I do feel that where the RCN is concerned, nutrition has fallen off the radar and this worries me – particularly in the light of the Francis Report where a lot of the concerns were about patients not being helped with food or drink.

I was invited to attend a meeting at the RCN, where the Chairs of each of the Forums were present, to discuss the issue and showcase the work of the NNNG. I hoped that this would provide an opportunity to network and perhaps invite some collaborative working with some of the forums and the NNNG.

I gave an overview of our work, what we stood for, and what had been achieved so far. I then gave a brief history of how nutritional care in hospitals had changed and how it was not now given the same level of importance, particularly by nursing, and bearing in mind all of the multiple national guidelines and recommendations that were out there. I then invited questions.

The questions were diverse to say the least. One of the chairs asked why relatives were not allowed in at mealtimes to help feed their loved ones. I think this is a pertinent question – many Trusts do not allow this and this is not the first time I have come across this query. I think with the push to establish Protected Mealtimes some wards have shut out those people who may of benefit and be able to improve nutritional intake for some patients. I would urge any of you whose Trust does not permit relatives in at mealtimes, to see if you can influence this practice. If clear guidelines exist regarding relatives being present at mealtimes they can be a bonus. They may mean the difference between an elderly person who requires help or a person with dementia eating their lunch or not. This is a simple change that, in light of the Francis Report, should be a priority and provide a cost free, positive outcome for some patients.

Another comment was that it was not only nurses who should be helping to feed patients – what about other members of the MDT – for example OTs, physios. I can only agree with this and this has been a topic discussed in one of the NNNG's CN columns in the past year!

Other points raised included the quality of hospital food, the introduction of fast food outlets into hospitals, and the shortage of trained nurses on the wards to ensure that patients were having their nutritional needs met.

So did my talk make a difference?

It was certainly well received, but I am not sure whether we will see a tremendous amount of collaboration between the NNNG and the RCN in the immediate future, or the appointment of a national RCN nutrition champion. However, on a positive note, the Gastroenterologist Nurses Forum are keen to work with us and I will be meeting them in the near future to discuss what we can do together. I still feel that the RCN should have someone who can be the spokesperson for nutrition and hydration, but with no current plans for this to happen I am concerned that it means that expert opinion on this very crucial aspect of care will not be offered by the RCN.

The RCN has received a lot of criticism recently for neither being an effective union nor a professional body. Perhaps that is where the problem lies. As an organisation the RCN is reactive as opposed to proactive. I would love to see a multidisciplinary nutrition committee – much like the Royal College of Physicians has. Their work is respected and cited. This does not appear to happen with the RCN and to my mind it is a great shame.

Nevertheless, I hope that by raising our profile with the RCN the various chairs of the forums will consider looking to us for advice and guidance regarding nutritional issues in the future, should they need it.

All we can do is watch this space!

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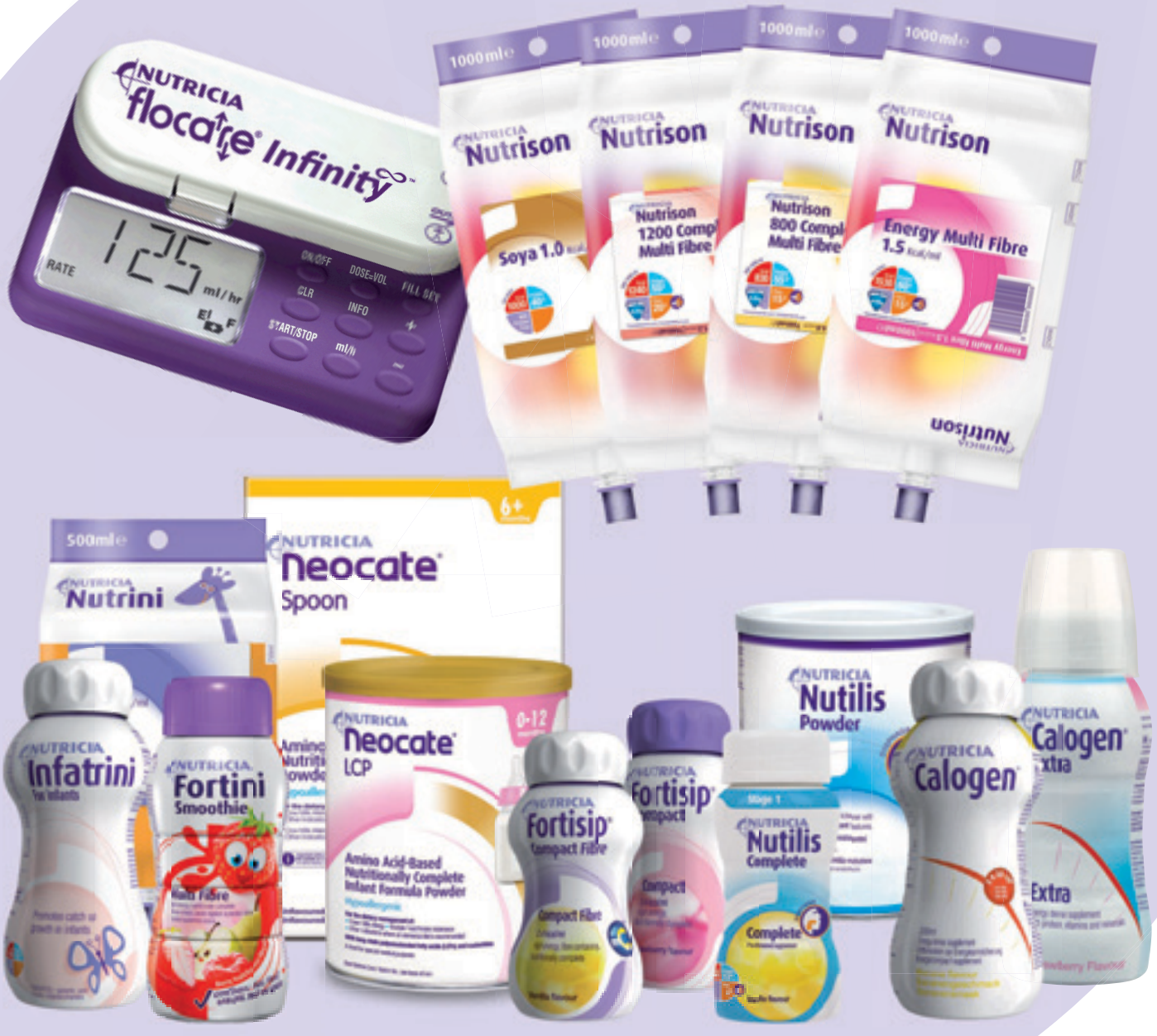

*MIMS, April 2012.

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April 2012

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