



PERSPECTIVES ON THE SPECIAL NEEDS AND CONCERNS OF HOME PARENTERAL NUTRITION PATIENTS

Marek Lichota – Association „Appetite for Life”



ESPEN-ONCA-MNI Joint Session

Kraków, Poland - 2 September, 2019

41st ESPEN Congress
on Clinical Nutrition & Metabolism

Nutrition - A Highway to Health



PATIENT JOURNEY TO NUTRITION SUPPORT



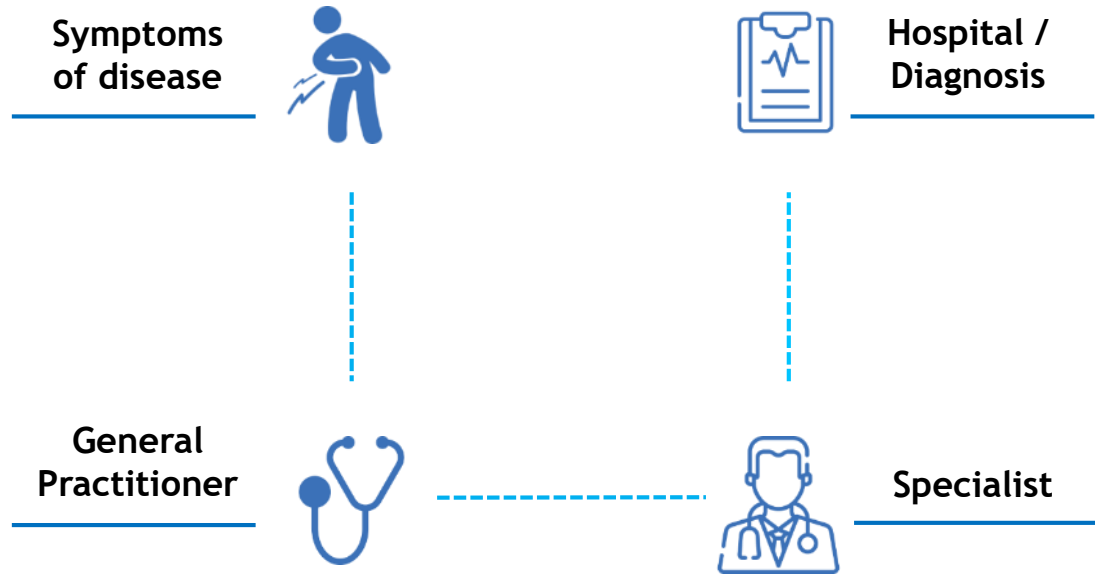
optimal
nutritional care
for all

Association
APPETITE
for life

mi
Medical Nutrition
International Industry

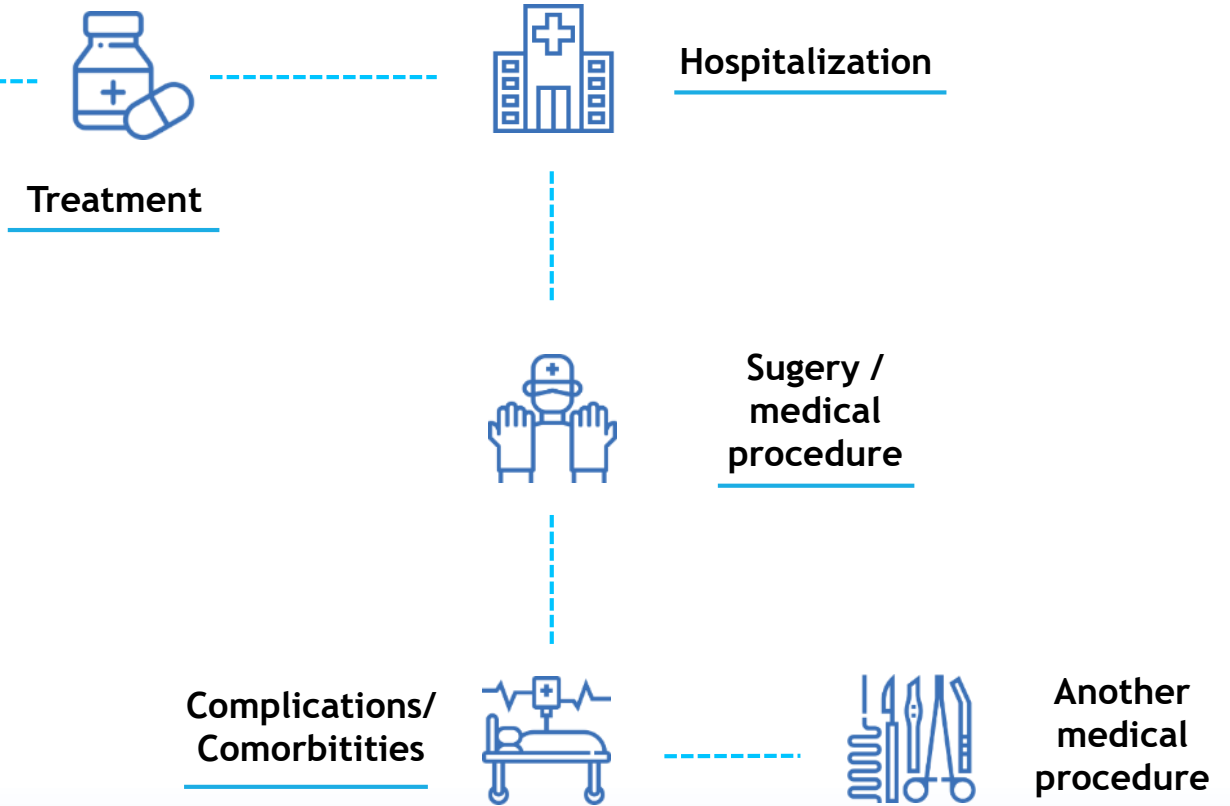


ESPEN
THE EUROPEAN
SOCIETY
FOR CLINICAL
NUTRITION
AND
METABOLISM





PATIENT JOURNEY TO NUTRITION SUPPORT





PATIENT JOURNEY TO
NUTRITION SUPPORT

Hospital



Nutrition
Center



Outpatient
Care

**Nutritional
assessment!**

Discharge
to home

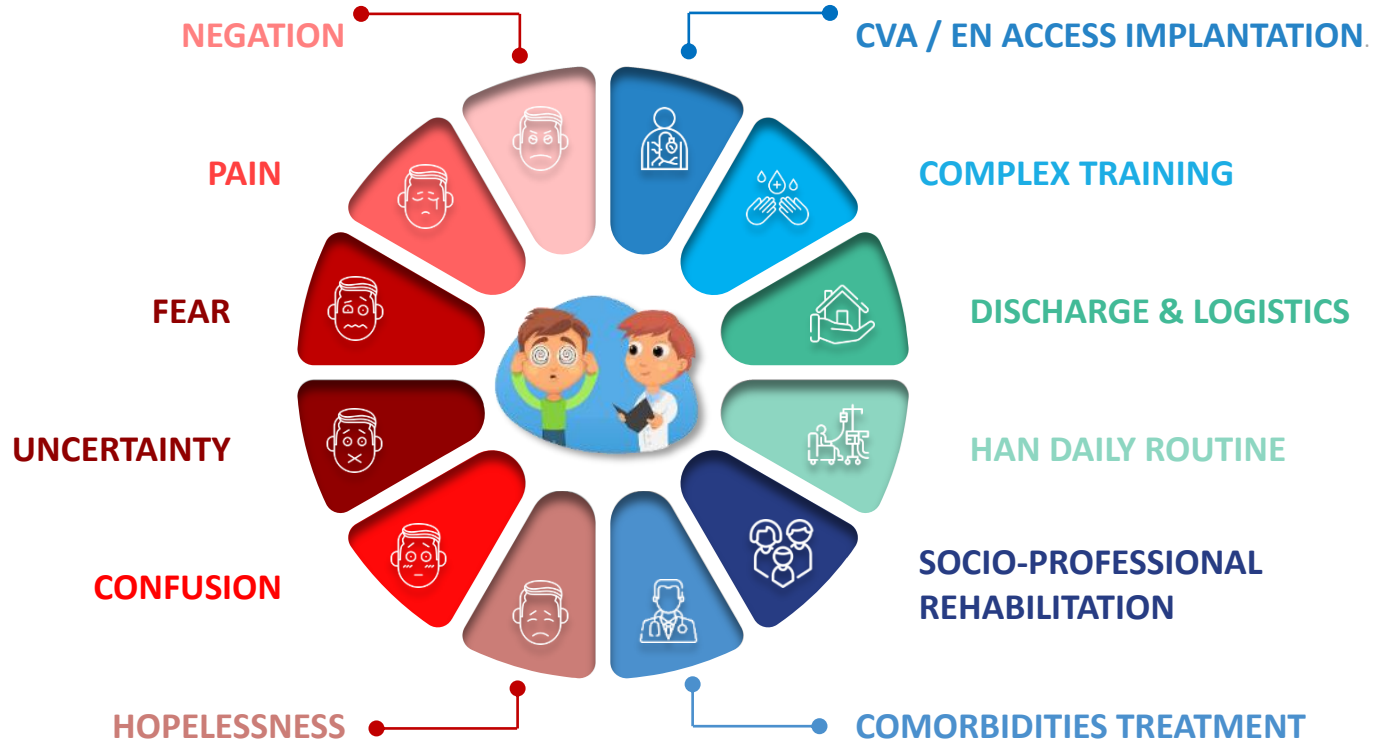


Significant
malnutrition





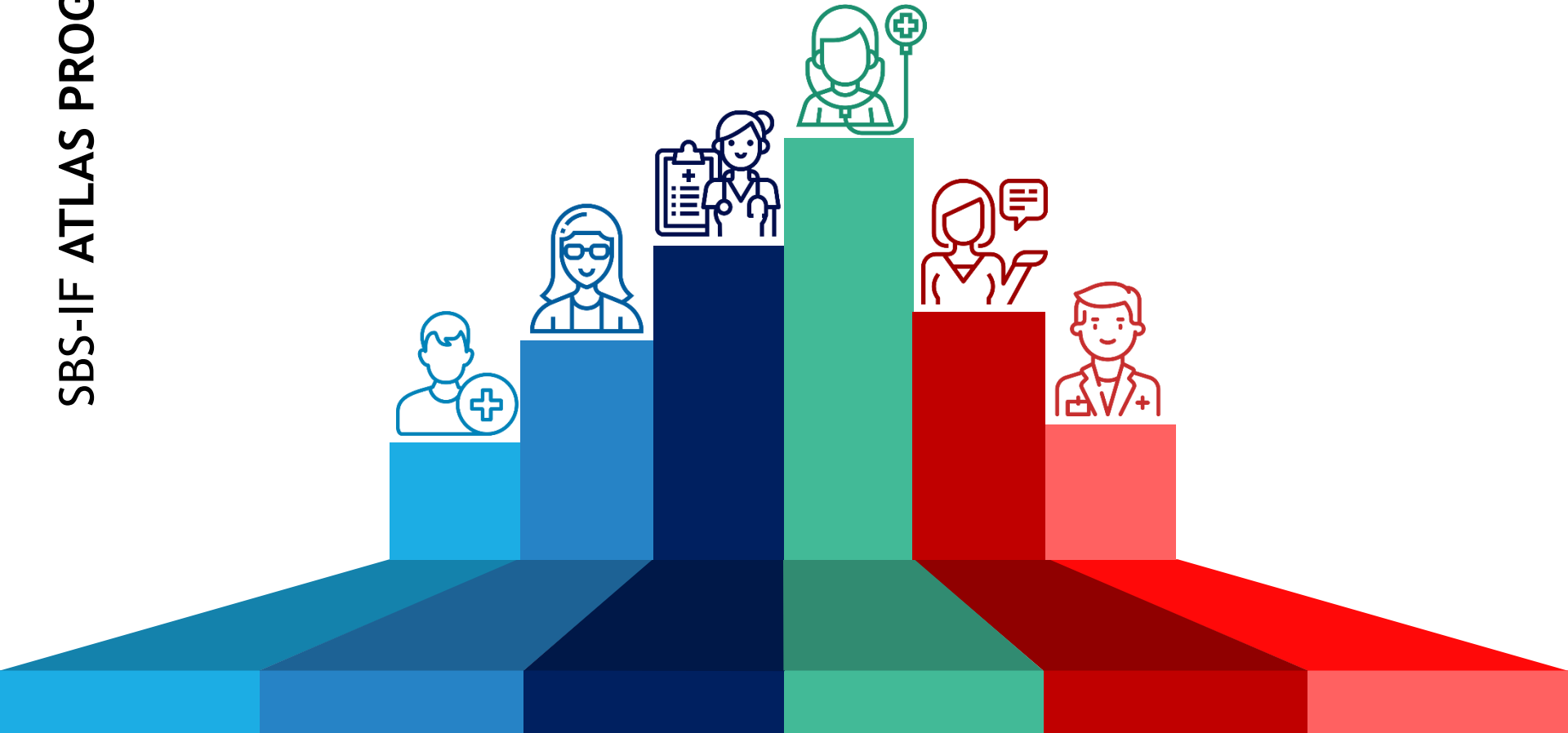
HAN PATIENT'S LANDSCAPE





SBS-IF ATLAS PROGRAMME

Six areas of urgent **unmet needs**, which are key to improve standards of **chronic intestinal failure care**.



Chronic IF is treatable, but there is inequality of access to treatment between and within countries.

1

There is a need to disseminate agreed epidemiology and quality standards within and between countries.

2

There is an opportunity to improve stakeholder understanding.

3

Current home and social care are inadequate to meet the quality of life needs of those living with chronic IF and their families.

4

There is inadequate research to drive service improvement.

5

There is a lack of accredited reference centres.

6





INEQUALITY OF ACCESS
TO TREATMENT

Svitlana Khodchenko

2 years old,
Dnipro (Dnipropetrovsk), Ukraine

Chronic intestinal obstruction,
Suspected Hirschsprung disease,
extended total colonic
aganglionosis. Intestinal failure.



<https://kiddo.ua/ru/child/hodchenko-sveta#null>



**DISSEMINATE AGREED
EPIDEMIOLOGY AND
QUALITY STANDARDS**





IMPROVE STAKEHOLDER UNDERSTANDING





optimal
nutritional care
for all

Association
APPETITE
for life

mi
Medical Nutrition
International Industry



ESPE
THE EUROPEAN
SOCIETY
FOR CLINICAL
NUTRITION
AND
METABOLISM

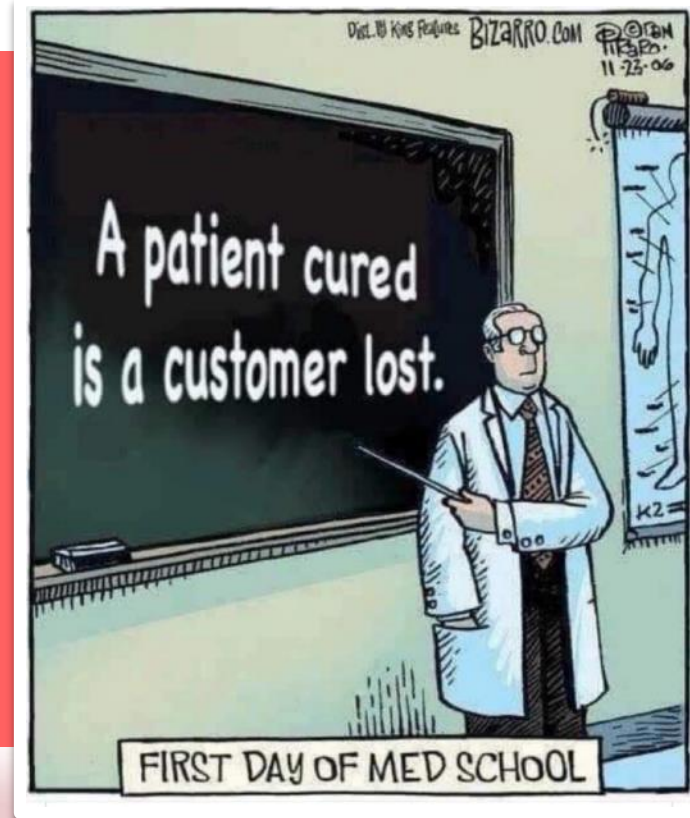


HOME & SOCIAL CARE
INADEQUATE TO MEET
THE QUALITY OF LIFE





**INADEQUATE RESEARCH
TO DRIVE SERVICE
IMPROVEMENT**





optimal
nutritional care
for all

Association
APPETITE
for life

mi
Medical Nutrition
International Industry

ESPEN



THE EUROPEAN
SOCIETY
FOR CLINICAL
NUTRITION
AND
METABOLISM



**LACK OF ACCREDITED
REFERENCE CENTRES**





NEGATION
that the patient won't be able
to take a part in a family life

PAIN
associated with
infected catheter
due to poor training

FEAR
of providing HPN to the patient
as there are a lot of myths
behind this therapy



UNCERTAINTY
if there is a chance to
continue treatment which
was on clinical trials.

CONFUSION
which nutrition center
I should choose
to provide best therapy

HOPELESSNESS
because there is no
HAN system in my country





NUTRI
POWER OF LIFE



We fall.
We break.
We fail.

But then,

**WE RISE.
WE HEAL.
WE OVERCOME.**





optimal
nutritional care
for all

Association
APPETITE
for life

mi
Medical Nutrition
International Industry



THE EUROPEAN
SOCIETY
FOR CLINICAL
NUTRITION
AND
METABOLISM



+48 600 270 882



Marek.Lichota@AppetiteForLife.info



LinkedIn.com/in/MarekLichota/



www.ApetytNaZycie.org/en

