Nutrition MATTERS in cancer

Insights from people receiving treatment for cancer in Ireland.

Niamh Rice
Director IrSPEN
Previs Healthcare Ltd.
Why are we still having to make a case for better nutrition in disease?

Hippocrates
‘In the face of illness, thin people do badly’ 460 – 370BC
The research explored what mattered to people, their thoughts, fears, experiences and what they believe would make a big difference.

- impact of cancer or its treatment on eating / nutritional status
- challenges they have encountered
- experiences of nutritional care

Stage 1:
Literature review, stakeholder engagement and data collection.

Stage 2:
IrSPEN National Survey of nutrition in cancer patients in collaboration with Dr. Aoife Ryan, UCC.

Stage 3:
In depth interviews with patients who received nutrition support.
Insights & Survey Evidence

1) Where are you on your journey?
Tell us about your diagnosis, treatment and its effects?

2) Food & nutrition
Have you experienced eating/dietary problems or concerns related to nutrition?

3) Nutritional care
What care, help or advice did you receive and did it make a difference/how useful has it been? What would have helped?

4) Sources of influence
Have you tried any diets or regimens, who do you trust for information, what are your sources of information and support?
Survey participants
1,085 completed/eligible for inclusion, 63% female:37% male (National gender ratio 51%:49%)

(Over representation of Breast Cancer under representation of Prostate Cancer reflects higher ratio of females: males recruited, with excess female participation via online recruitment)
Sheila’s story

• Retired School teacher
• Fit, hill walker, loved outdoors
• Autoimmune hepatitis (long duration)
• Cancer (GIST) diagnosed 2004
• Extensive surgery/post op nutrition support
• 2018 – seen by dietitian as palliative patient

2017
“I had oedema from my toes right up to my knees. I got a chest infection, I couldn’t eat, I was in a terrible mess…”

Final treatment option early 2018
“The second week of the new treatment, I started to stagger, I couldn’t use my hands, my mouth and my gums were so sore, my throat closed over, I was running in and out to the toilet every hour…so I said that’s it. I’ve had enough. I couldn’t eat. I had lost 6kg by then..”
Dietetic Consultation

2018 agreed to see dietitian (Reluctantly)

“She was absolutely wonderful and she changed my diet, gave me different drinks to try and she assured me that there was no fat in them and she was very careful of my liver. She recalculated the dose of enzymes and how I was using them and it made a HUGE difference..

I had no diarrhoea, I couldn’t believe it!… my appetite returned, I was able to walk, I had energy, I didn’t feel I was dying anymore… I now can eat every meal of the day. My throat will actually accept food. In the time since I last saw the dietitian, I have put on 2 kg.
“Really, she saved my life. I’m able to meet my friends now for lunch, I’m able to have visitors, I wasn’t even able to see my own family because I didn’t have the energy. Can you imagine the energy I have?”
I can walk the beach...

I can walk the beach!!
What difference has it made?

“Honestly, I’d given up.

I looked like a corpse...
When I looked in the mirror, I said..
‘Sheila, you really are on your way out this time’.
By this time, I had settled my affairs. I was going to ask how long do I have.. but afterwards, the way I felt, I thought…I’m not going to ask. I’d just be putting a time limit on it. Instead, I’m going to live each day”
Survey Results (n = 1085)
How do you rate the importance of nutrition support, advice or care in your cancer journey?

9 in 10

Considered nutrition (advice, support, maintaining good nutritional status) extremely / very important

NUTRITION IS IMPORTANT TO PATIENTS

- Extremely important: 58%
- Very important: 31%
- Somewhat important: 9%
- Not so important: 2%
- Not at all important: 0%
Have you experienced problems with your diet or nutrition?

Nearly 1 in 2 patients (n =454, 45%) said they had experienced one / multiple problems for which they required help/support.
“I would look forward to a meal but when the meal would arrive, no, no .. I don’t know what it was, but the minute it was sitting there ready for me – I just couldn’t eat it, I couldn’t even face it.”

Paul, GI cancer, 14 years since diagnosis, regaining weight with nutrition support / advice from oncology dietitian and outliving all expectations

APPETITE LOSS IS COMMON & CHALLENGING

- Appetite
- Weight change
- Difficulty eating
- Knowing what to do
- Bowels
- Taste changes
- Nausea/vomiting
- Intolerances, aversions, cravings
- Other
- General anxiety about nutrition
- Dysphagia, ondontological
- Upper GI symptoms
- Difficulty with diet
- Mouth
- Fatigue

0 20 40 60 80 100 120 140
Since your diagnosis, has your weight changed? If you have lost weight, did this happen without you consciously trying?

Weight changes experienced by patients surveyed \((n = 1061)\)

10.4kg \((0.9 - 44kg)\)

Mean weight loss reported

REMAINING WEIGHT STABLE IS THE EXCEPTION

21% of ‘involuntary’ weight losers were happy/delighted to have lost weight, 34% indifferent and 45% unhappy/very unhappy, indicating they were unaware of the clinical significance of weight / muscle loss.
Half of all patients (52%) noticed a lot / some muscle loss. Experienced noticeable muscle loss, although none linked to their disease or treatment.
42% said they were always or mostly asked about diet / nutritional problems

Are you asked about nutritional problems?

84% are always or mostly weighed at clinics

6 in 10 say they are occasionally, rarely or never asked about diet/ eating problems?
Why are nutritional problems overlooked?

“Paul was being weighed, yes, but they didn’t do anything with it or mention it. *I think his oncologist was trying not to worry him.* I have a record of his weight though – I used to occasionally say, he’s down another kg. At this stage, he had lost 3 stone and his BMI was 17 point something...”

“I think the focus was entirely on the cancer – no one looked at anything else that was going on..”
67% seen by a dietitian had experienced significant weight loss.

Have you seen a dietitian at any point?

39%

Seen by dietitian at some point in their cancer journey

67% seen by a dietitian
Patients with unplanned weight loss had not seen a dietitian or been assessed/treated.

n = 183 patients received ONS and n = 39 food fortification advice, but only 1/3 of those with unplanned weight loss (n=132) received ONS.
74% of patients rated dietitian visit as ‘extremely/very’ helpful
Breda’s Story

- 40’s business woman
- Breast cancer diagnosed 2016
- Sepsis early 2017
- Intractable vomiting –
- TPN (23 days)
- Tube feeding
- Diet plus ONS

“.. My appetite went backwards from when I was first diagnosed. I couldn’t eat any food – no matter what it was. When you’re not feeling well, the smell of any food will make you sick. I was sick of getting sick and I preferred not to eat so as not to be sick…”

Peace of mind

Once Arun told me what to eat and explained why, I just didn’t listen to everyone around me – it was fantastic to have access to an absolute expert. No more googling and listening to people putting their oars in..”
What happens in the void?
“I was very weak and nauseous post stem cell but didn't get any help or advice. I learned a little from others on treatment. Was still unable to eat when leaving the hospital in 2016.”
Multiple Myeloma Patient, 12kg unintentional weight loss, severe nutritional problems

“Have lost 4 stone – very concerned. Wasn’t offered any treatment or advice. Trying to put on weight.”
Multiple myeloma patient, 25kg unintentional loss

I had a mixture of problems - constipation, diarrhoea, loss of appetite and everything in between. Worried about weight loss but no advice and didn’t see a dietitian.
Lung cancer patient, 10kg loss to date

“Loss of appetite. Change to nil taste buds. Nausea from some smells, some food texture or taste. Huge weight loss. Food boredom. Anxiety!”
Breast cancer patient, 16kg weight loss, no nutritional care, no interventions.

I have had no dietetics since my colorectal diagnosis apart from research I do online. Especially related to hospital diet during stay, diet for stoma, more individualized care.
Patient with synchronous cancer, weight/muscle loss, multiple nutritional problems.
"My oncologist said that I would lose weight but not how to manage that. I have lost 22kg and am now 7stone. I read ‘the anti-cancer’ diet but I don’t have the energy to work out a diet although I have worked out what I can stomach– mainly orange ice-pops but I wish someone could help me with that”.
36 year old patient with melanoma, (spread), no nutritional care or advice, still undergoing treatment.

“Younger people with the disease have access to information online. Older sufferers are not so well informed so are more likely to need this information supplied”
Urological cancer patient, metastases confirmed, tried ketogenic diet and fasting.

“During treatment and now I have received no nutrition advice bar the ICS booklet. During treatment I found it hard to eat and cook. Now I think every food will bring back my cancer”
How they use social media

It's about living in the moment, not having to wait and getting instant feedback and then it's scrolling on to the next post.

13%

Tried diet ‘cures’ and anti cancer diets – including patients with metastatic disease and significant weight loss. Over 65s least likely to do so (5.6%)
What does all this mean

As we explored what was important, some themes emerged that can help the NCCP and those caring for cancer patients understand what they need help with:

- **Living well** not just surviving
- **Personalised care** vs One size fits all
- **Treating the patient** vs treating the cancer
- **Peace of mind** vs anxiety
Patients are concerned & confused

Do you feel bombarded with information in the media? Are you confused? (I in 2 say yes)

“Scared to eat everything. Gave up meat. Began to eat really unhealthily. I considered vegan diet. No motivation due to fatigue from treatment. No nutritional advice offered. HSE Booklet given. Still all over the place!”

“In many ways, all the information is overwhelming because it can be very conflicting also. Hard to know what to believe and which advice to rely on..”

“I don’t know what to eat anymore”
To be honest I feel very written off....

“ I keep thinking.. I have not been offered the service because I am on death row and come low down on the 'need' for this service. This is probably just me overthinking but it is truly how I feel at times when coping with food is just too much effort and yet it seems to be all I think about to keep alive. I am worried at times. Sometimes I look scary and that worries me.

Cancer first diagnosed 2006, metastatic disease, 16kg weight loss, never referred to dietitian
‘The problem is that neither my oncologist or surgeon felt that my diet was in any way important’

Colorectal cancer patient
What do patients say they need?

“If patients were given proper information by a hospital dietitian before treatment begins, we would not be so easily influenced by media”.

“It would be helpful if the professionals would engage fully with what is out there instead of dismissing everything out of hand, because then you feel like anything could be true.”
If 13% found in this survey holds for all patients living with cancer in Ireland, then the numbers at risk from ketogenic diets, fasting and other unproven cancer diets could be in the thousands...

This IS a representative survey.

Every 1% of patients is equivalent to 1500 patients that may have poorer outcomes due to misinformation and diets that exacerbate muscle/weight loss.
“From someone who was having to go to the bathroom 10, 12 times a day, he is now able to go out and visit people. He had literally lost all interest in food and was losing even more weight at Christmas, but she put him on drinks (ONS) twice a day, got him to take the right dose of enzymes to help his digestion and his weight is now going up again for the first time since his diagnosis.”

Wife of cancer patient

“If only I had seen the dietitian 14 years ago. I have outlived all expectations but I’m putting on weight and enjoying my food again. I feel 100% better. She has literally given me back my life again”

Paul, cancer patient with St. James’s hospital
How health economics of malnutrition work

Malnutrition Cliff

Ahhh!!

ouch!

somebody help me!

R.I.P
Early screening and nutrition support at first sign of risk prevents the patient having to be rescued, at ever increasing cost and diminishing return.
“Where do you start?.. There is a huge gap between the medical profession in dealing with cancer and working with patients on their diet and nutrition. There is no information in any of the clinics I attended, no leaflets, no follow on, it's not even offered as part of the consultants assigned to your case. I've been poked and prodded but no one has seen me about my diet.”

*Breast cancer patient, muscle loss, very concerned about diet / nutrition.*
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<th>Three things we could start doing now to make a difference</th>
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<td>Prevention of malnutrition and preservation of muscle mass recognised as a key goal of cancer care</td>
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<td>Nutritional care built into cancer strategy and care pathways</td>
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<td>Effective communication of role of nutrition in cancer care</td>
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Malnutrition in cancer is not inevitable or inconsequential. Evidence based recommendations for nutrition support in cancer are not being implemented in Ireland, leaving many patients without the opportunity for best outcomes. This urgently needs to change.

"I want to live until I die, I don’t want to fade away"
Nora Rice, August 27th 2011

Every cancer patient deserves good nutritional care
Thanks to Breda, Larry, Paul, Grace, Sheila, Fiona, Peter, Helen, Nora and all the patients that shared their stories..

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- Breakthrough Cancer Research