Ann Edgar Trust

Ronny Allan – patient perspective and journey

Living with Neuroendocrine Cancer

31st August 2022

Disclaimer

I’m not a doctor or any form of medical professional, practitioner or counsellor. None of the information in this presentation or on my website (RonnyAllan.NET), or linked to my website, or conveyed by me on any social media, should be interpreted as medical advice given or advised by me.

Disclaimer

The **Heterogeneity** of Neuroendocrine Neoplasms (NENs)

Neuroendocrine neoplasms are known to be a group of heterogeneous cancers, meaning *"consisting of different, distinguishable parts or elements"*. This starts with pathology where the tumour cells can be different in colour, shape and size, and lead into different prognosis and therapies. But it also includes these terms as a

Neuroendocrine Tumour (NET) means well differentiated and can be Grade 1, 2 or 3

Neuroendocrine Carcinoma (NEC) means poorly differentiated which is Grade 3 by default

Neuroendocrine Neoplasm (NEN) is an umbrella term for both well and poorly differentiated *(although I (and others) may sometimes say Neuroendocrine Cancer to mean the same).*

Disclaimer

The **Heterogeneity** of Neuroendocrine Neoplasms (NENs)

Words are important in a general discussion:

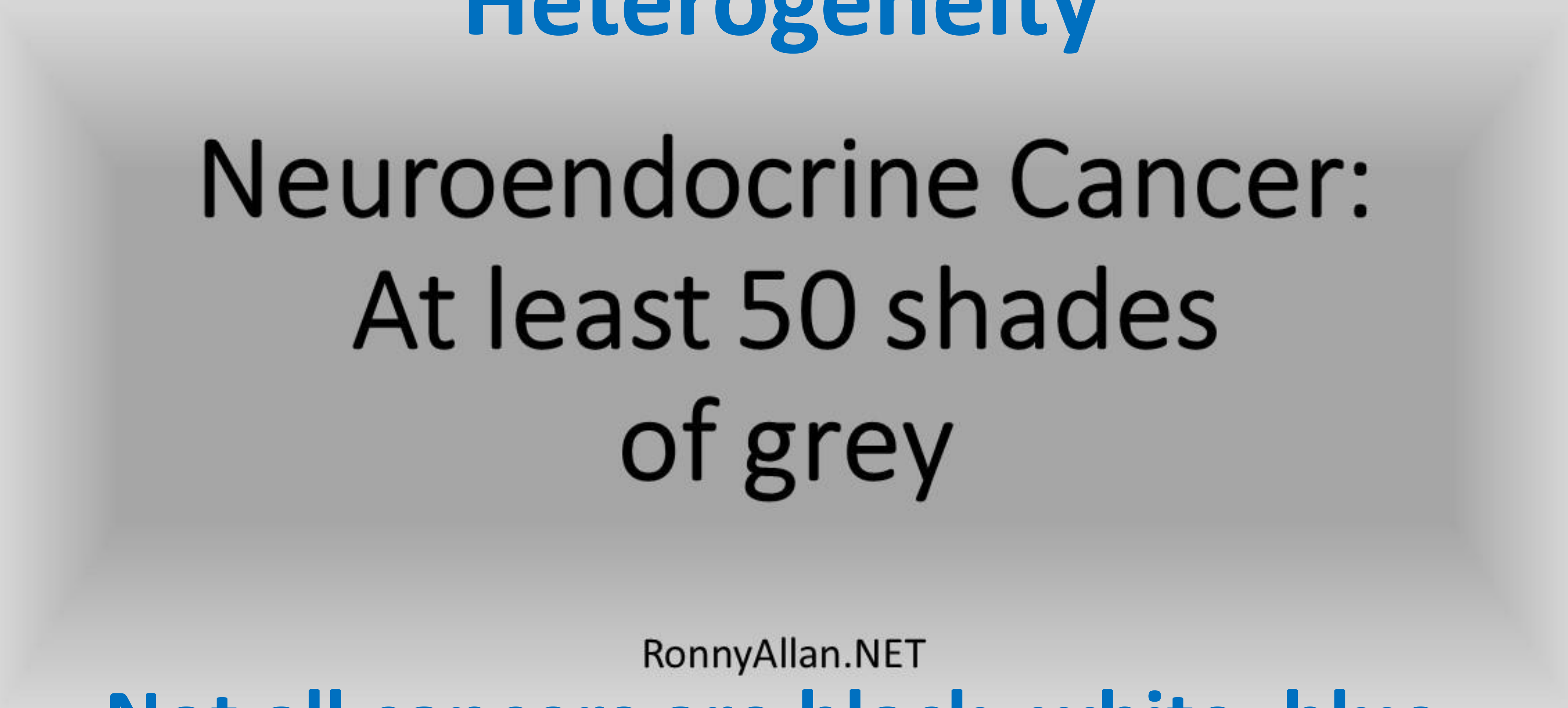
I like to extend heterogeneity to many other areas because it's important in patient groups and discussions for context, e.g.

- Even with the same type of NEN, people will have different stages, i.e. some localised, some with regional metastases and some with distant metastases. Epidemiological data confirms some types are more or less likely to metastasise than other types.

- Some will have functional tumours (distinct syndrome), others will be non-functional. Even with the same type, there can be different functional tumours, e.g. Pancreatic NET has around 7 or 8 different syndrome types.

- Some will be hereditary, most won't

Heterogeneity



Neuroendocrine Cancer:
At least 50 shades
of grey

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Not all cancers are black, white, blue, pink …… some are very grey

Who am I?

- Born Dundee 1955
- Joined the Army in 1972, settled in south coast of England 1991. Left the Army in 2001 to work in industry, retired 2014.
- Married with a son and daughter, 4 grandsons.
- Living with wife Chris close to the New Forest in Hampshire
- Diagnosed metastatic SI NET in 2010

Diagnostic Triggers

- May 2010. Weight loss, low haemoglobin, iron deficiency anaemia following a routine discussion with a nurse. *……in hindsight also signs of carcinoid syndrome, e.g. flushing and diarrhea ….negative colonoscopy Sep 2008.*
- Late June 2010. Holiday in Barbados not realising what they were about to find.
- 8th July 2010. CT found multiple liver metastases, 3cm mass in root of mesentery, extensive intra-abdominal spread (bulky chains of lymph nodes), incidental lung nodule, "Retroperitoneal Fibrosis" close to my aorta (…surgeon described it as "desmoplasia" and more about that later).
- 19th July 2010. Liver biopsy – Grade 2, Small Intestinal Primary (SI NET). Following diagnosis an Octreotide Scan in August confirmed more hotspots: left axillary nodes (armpit), left supraclavicular nodes (near collar bone). Both Chromogranin A and 5HIAA elevated approx. 3 x normal range.

Nurse: ***"Did you mean to lose weight?"***

Me: ***"No"***

Doctor: What are you doing this afternoon

Me: Whatever you want me to do

I didn't feel unwell

The Specialist Postcode Lottery

- Secondary care specialist referred me to an Oncologist in Bournemouth who knew about NET
- Oncologist said he would become my main point of contact and that he would eventually be referring me to one of UK's top GI and NET surgeons who also worked with an interventional radiologist …..
- Oncologist: "…… but first I need to do a bunch of tests"
- Me: "Let's go!"

Surgery and other treatment

- 2010 (Aug) – test test test, CgA, 5HIAA, Octreotide Scan (hurry up and wait)
- 2010 (Sep) – daily octreotide pending surgery. Met the surgeon ………. “I’m going to give you a hard year”
- 2010 (Oct) – bland liver embolization
- 2010 (Nov) - SI resection (terminal ileum) and lymphadenectomy/right hemicolectomy, desmoplasia stripping from aorta/inferior vena cava (IVC). 19 day stay complete with post operative seroma repair and a minor infection
- 2010 (Dec) - Lanreotide
- 2011 (Jan) – Pulmonary Emboli – anti-coagulants
- 2011 (Apr) - liver resection circa 66% removed (keyhole)
- 2011 (Jun) – aborted TACE due to “new plumbing”
- 2012 (Feb) – lymphadenectomy left axillary and left clavicle (SCF nodes). Axillary positive, clavicle negative
- 2013 – large thyroid “lesion” formally reported, left SCF nodes still lighting up.

Apart from that I'm OK!!

You guys might empathise with this?

Normally slow but sneaky

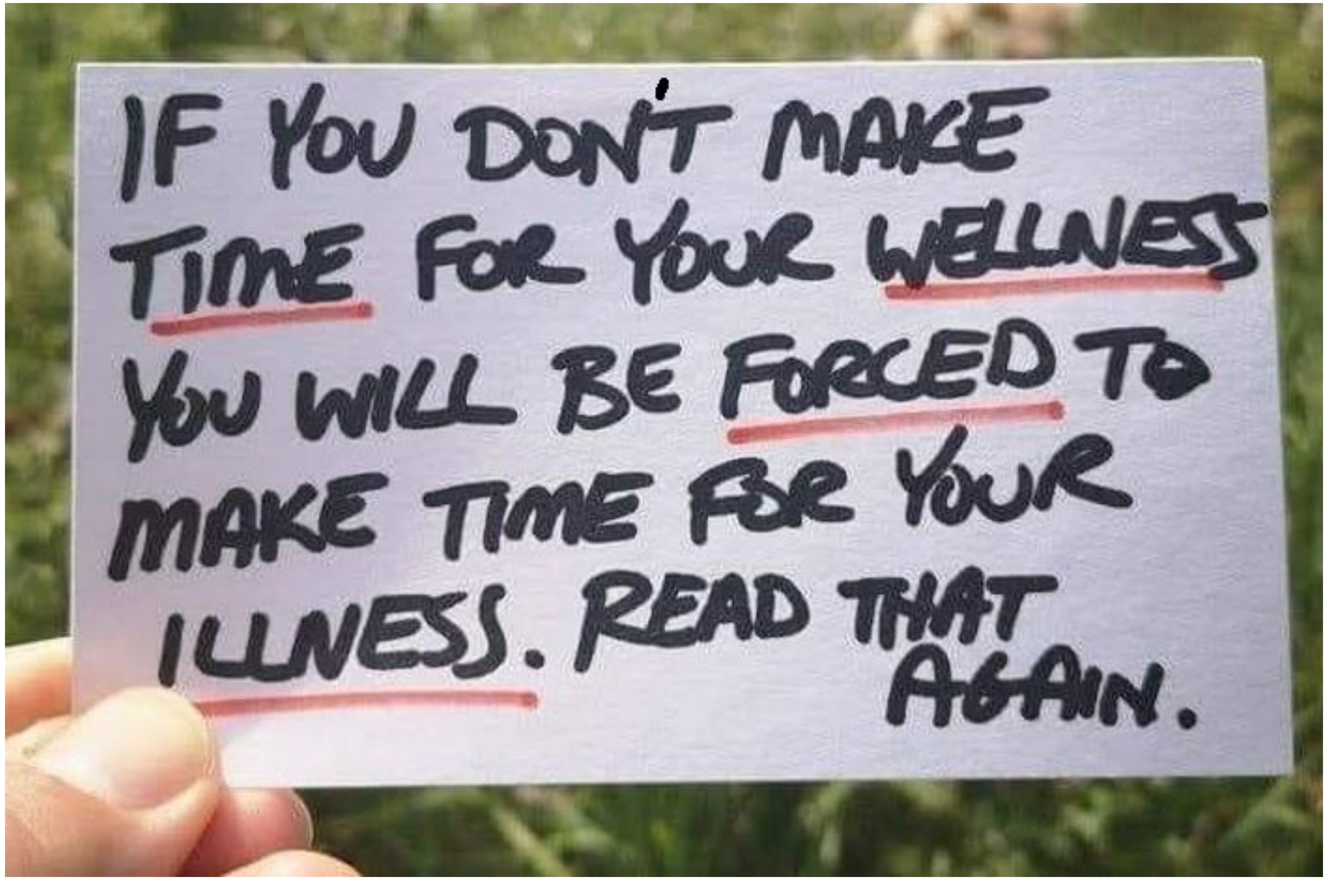
How could a cancer cause so much damage without a grand announcement?

I thought I was going to die ……….

My patient story

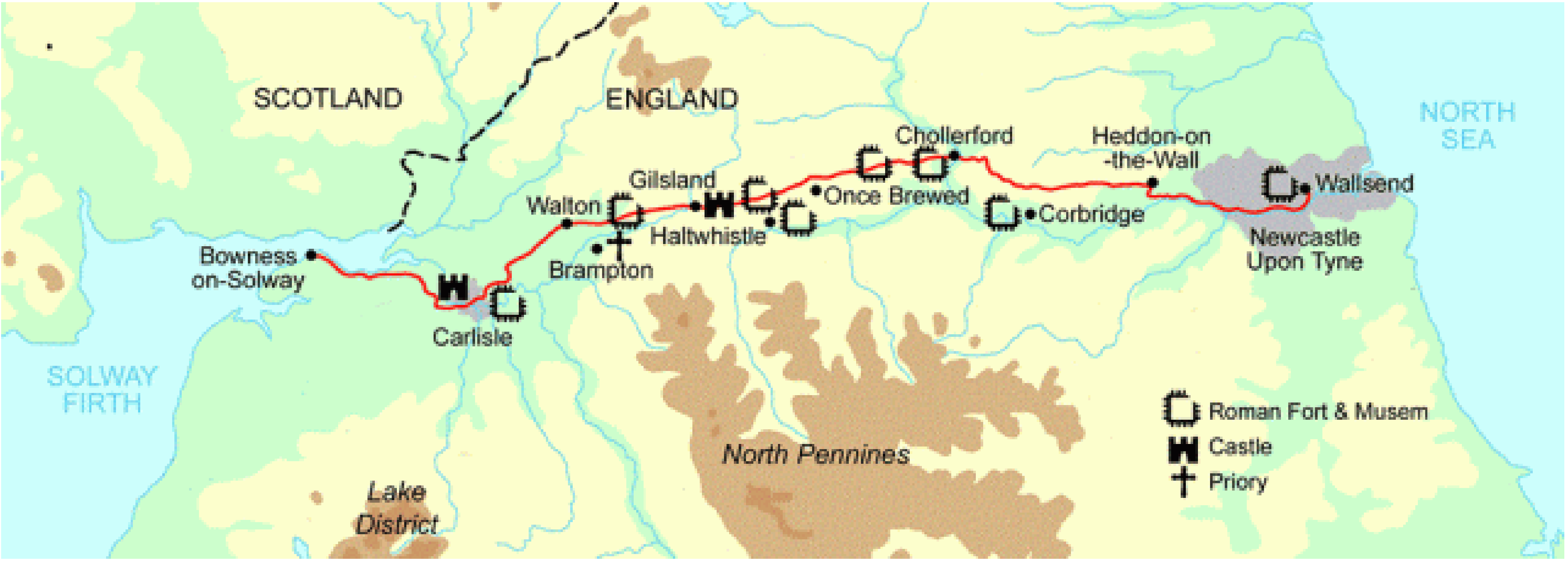
How did I move on from this?

The turning point



IF YOU DON'T MAKE TIME FOR YOUR WELLNESS YOU WILL BE FORCED TO MAKE TIME FOR YOUR ILLNESS. READ THAT AGAIN.

I said in 2001 I would love to do this ……



…. I finally did it in 2014, nice one Centurion

End of the walk at Bowness-on-Solway

I also gave up work in 2014

I realised I wasn't going to die ……….

……….. I was going to live!

Taking the piss

Tumour markers and 5HIAA stable since summer 2012

I’m stable but I still need support and surveillance

Surveillance and Follow-up

- **Thyroid 'lesion' growth** – **2013-2016** – 16x19mm, several biopsies inconclusive. Mild hypothyroidism – levels stabilised by thyroxine supps. Passed back to NET MDT by Endo – same surgeon who carried out my lymphadenectomy in 2012
- **Pulmonary emboli.** Changed from anticoagulant injections to 2 x daily tablet. I pushed this – I'd had enough
- **2014-2018** - 6 monthly CT, stable. BUT CT in 2018 reported progressive retroperitoneal fibrosis (new Onco)
- **2018 – very first Ga68 PET/CT** - added one rib lesion (right 11), clavicle area nodes still light up, thyroid still lights up, more nodes above the diaphragm light up. Retroperitoneum and liver activity (but these are stable on CT).

Surveillance and Follow-up

- **Retroperitoneal Fibrosis 2018 alert**

  - A reminder - 2010 diagnostic scans reported *“a rim of abnormal tissue surrounding the mid and distal aorta, up to 15mm in thickness”.* Surgeon stripped much of it from aorta 2010 (270° clearance)
  - CT observation in 2018 (new Onco) - quite close to left ureter
  - MDT guidance: worst case surgery required, possibility of stenting. Special kidney scan ordered
  - A renal MAG3 PET confirms 60%/40% split on kidney function. Decision = monitor

Surveillance and Follow-up

- **Lanreotide and/or malabsorption side effects?** Started using Pancreatic Enzyme Replacement Therapy (PERT) Dec 2018. (June 2018 - mild pneumonia – lost 10lbs)
- **Lanreotide side effect?** HbA1c/blood sugar spiked in 2018 to pre-diabetes. Was a one off, within reference range since but often borderline. Too many Tunnocks, Macaroon Bars and Tablet?
- **Nutritional/side effect screening.** NET nurse led. Blood glucose, thyroid panel, lipid panel, vits B9, B12, ADEK (in addition to standard Chromogranin A and 5HIAA). Moved to 5HIAA plasma version – no more lug a jug …yay….
- **Routine Surveillance scan** – CT changed from 6 monthly to 12 monthly in 2020. 10 year point

Surveillance and Follow-up

- **July 2021 – 2nd Ga68 PET/CT** - more or less the same as 2018 but more activity in clavicle/subpectoral area – probably reactive.

- **June 2022 – routine CT** – stable disease but ground glass opacity showing in left lung. Recent COVID infection. Rescan in 3 months.

- **Oct 2022 – repeat CT scan** – tbc.

Sometimes I feel like I’m still doing this ….. but it seems much more manageable!

Who am I?

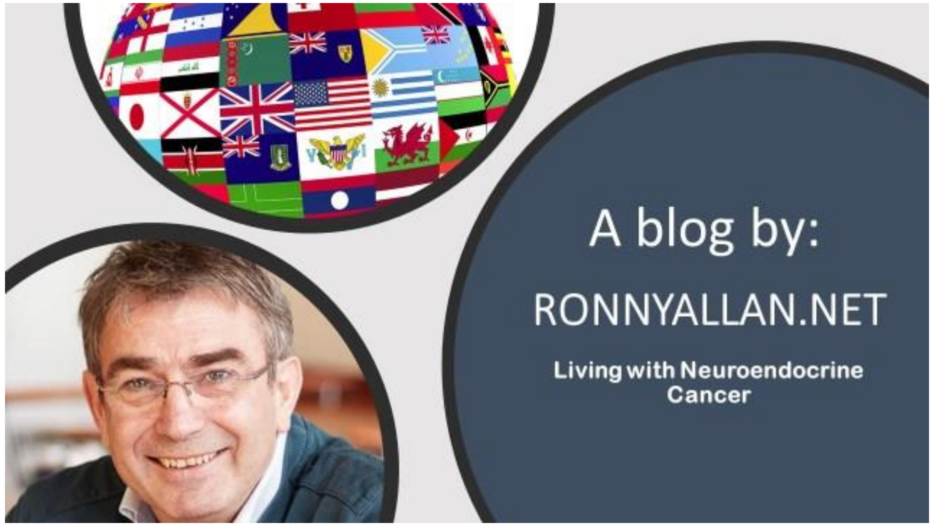
A patient blogger but also a self declared independent advocate and award winning patient leader


THE ORIGINAL

NEUROENDOCRINE CANCER SITE
BY RONNY ALLAN

Search @NeuroendocrineCancer

https://www.facebook.com/NeuroendocrineCancer.RonnyAllan


A blog by:

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Living with Neuroendocrine Cancer

NEUROENDOCRINE
CANCER

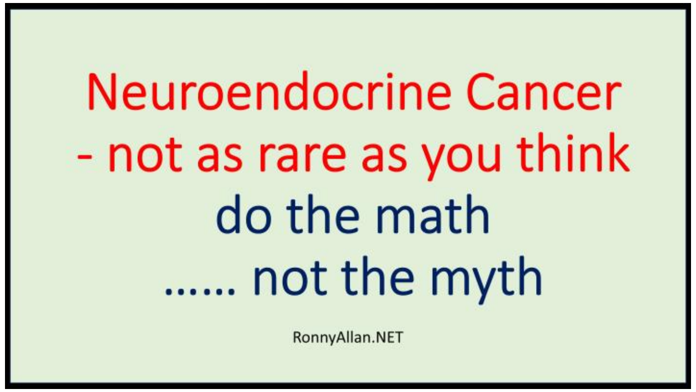
BEST IN SHOW:
COMMUNITY/FORUM

wegohealth
health activist awards


Lifetime Achievement Winner
WEGOHEALTH
AWARDS
RONNY ALLAN

WEGO HEALTH AWARDS
BEST IN SHOW:
BLOG
WINNER

A patient blogger but also a self declared independent advocate and award winning patient leader



Neuroendocrine Cancer
- not as rare as you think
do the math
…… not the myth

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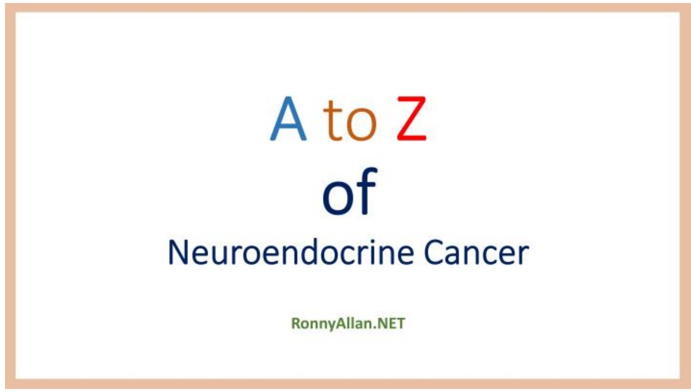

A to Z
of
Neuroendocrine Cancer

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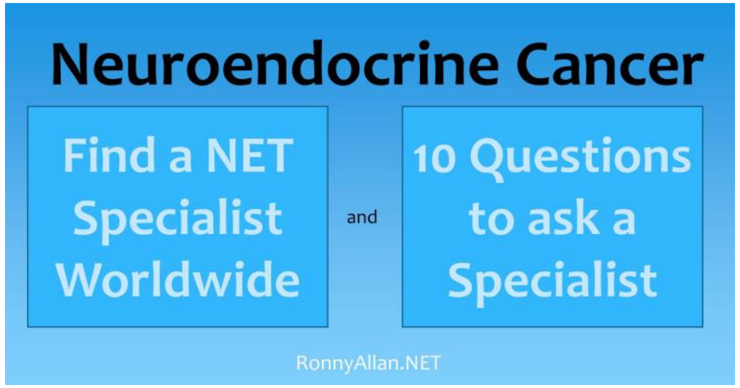

Neuroendocrine Cancer

Find a NET Specialist Worldwide

and

10 Questions to ask a Specialist

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IGNORE THIS POST

Neuroendocrine Cancer will be pleased – it hates awareness

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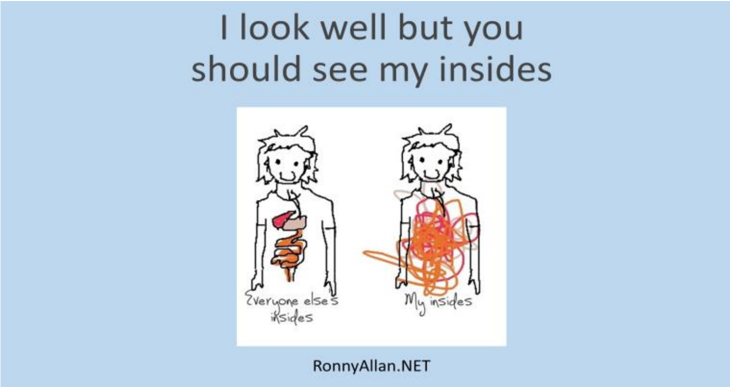

I look well but you should see my insides

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Self advocacy

"Doctors might be the experts in cancer but you're the expert in how cancer has affected you... Value your expertise."

Self advocacy

- **The best advocate for you is ……. YOU!**
- If in anyway possible, see a specialist (or a doctor working in coordination with one)
- Advocate for yourself (or find someone who can)
- Know your baseline diagnosis and track it
- Ask questions:
  - do not be afraid of appearing foolish
  - do not be afraid of healthcare professionals ……
- Ask for 'quality of life markers' not just 'tumour markers'

Living with NETs - 12 years on

Next milestone (cancerversary) set for 70

Another "hill" climbed

Living with Neuroendocrine Cancer

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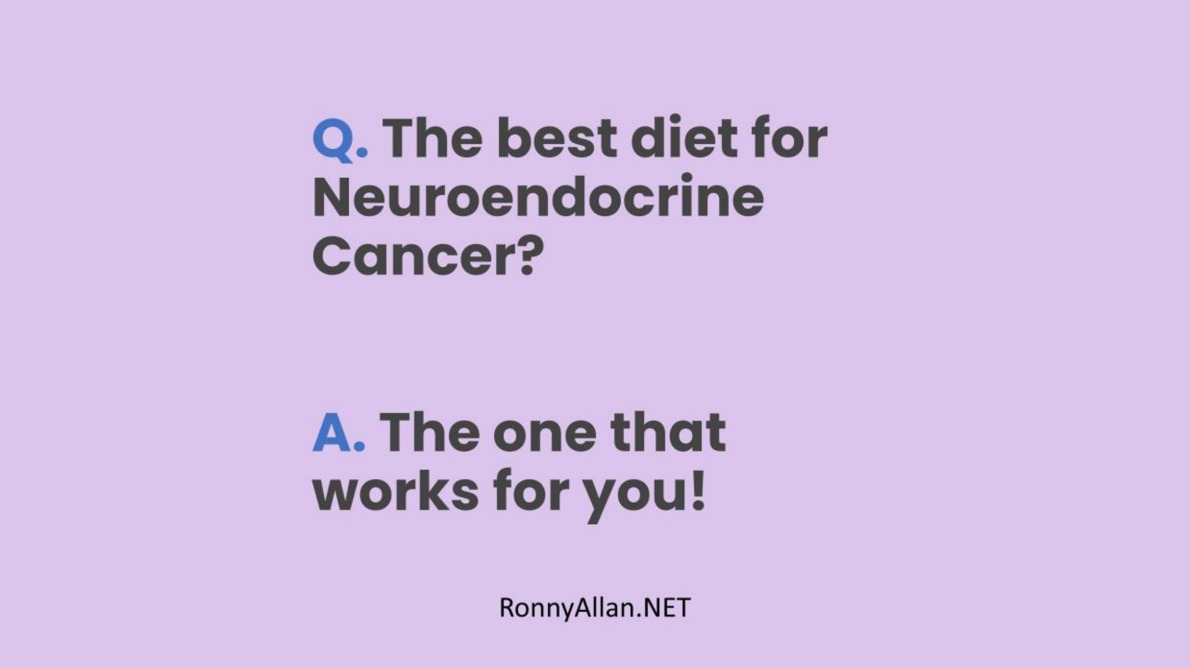
for me it’s about appetite …… risk appetite

...i.e. the level of risk that you are prepared to accept in the pursuit of quality of life

Risk vs Benefit

Living with Neuroendocrine Cancer

- ………. but it’s also about food appetite!
- No single diet will work for everyone
- Eat what works for you – e.g. pancreatic NETs may
  have different issues than Small Intestine NETs.
- Experiment and keep a diary
- Maintain weight if possible, lose weight if you need to
- Stay fit



Q. The best diet for Neuroendocrine Cancer?

A. The one that works for you!

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Waiting on my brontosaurus and chips

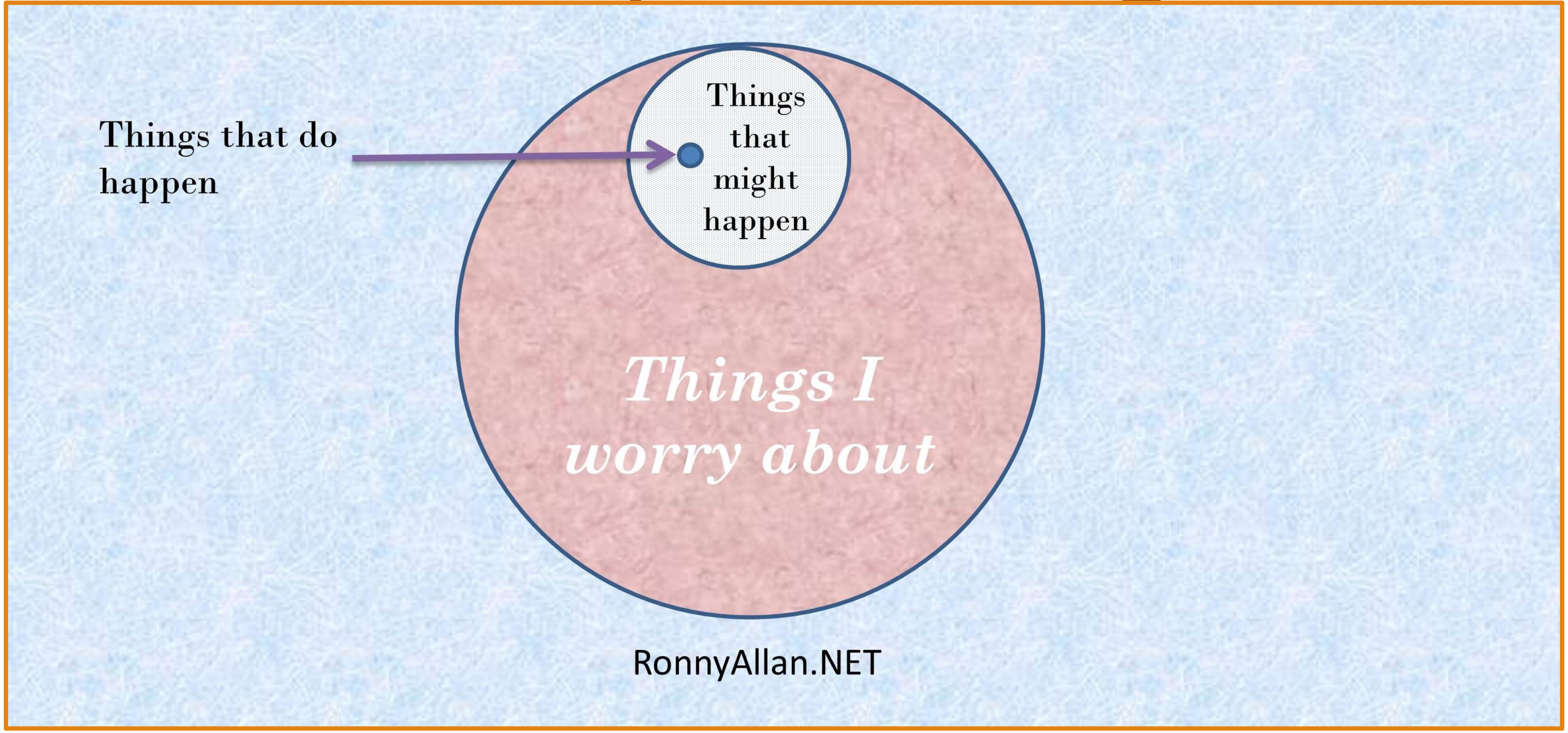
Photograph by Wilma Flintstone

Top tip – keep your sense of humour

Conquering Fear

1. Accept your diagnosis
2. Accept the road ahead might be bumpy
3. Identify your triggers
4. Talk about it
5. Social media/internet is a positive for some but it can sometimes have the opposite effect
6. Be patient - not be a patient (NETs in particular can be a long journey)
7. Focus on wellness as well as illness – see the positives
8. Seek counselling if necessary

A way of thinking



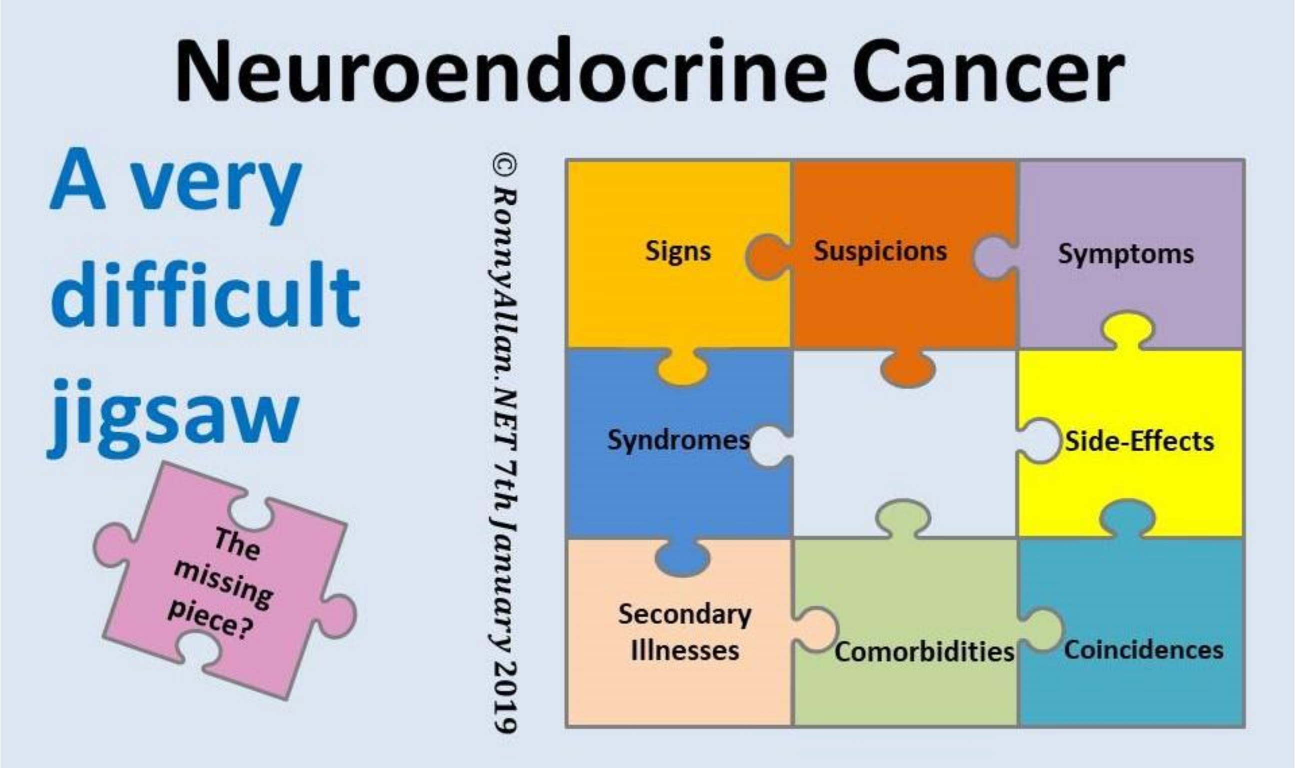
Finding Perspective (….don't sweat the small stuff)

Living with Neuroendocrine Cancer as a chronic disease

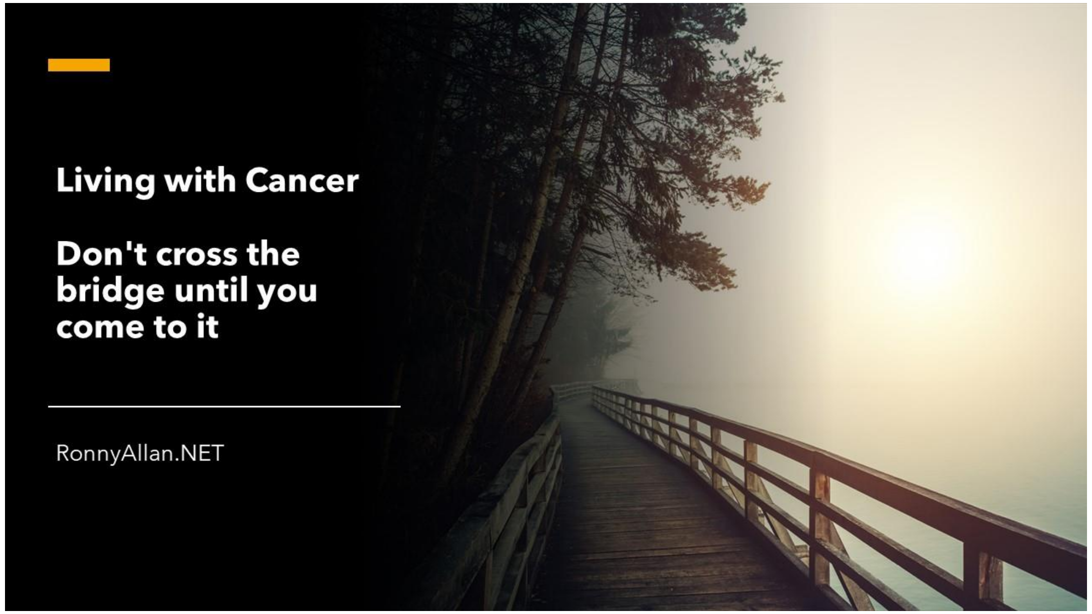
- Not everything is connected to NETs.

- "*Even NET patients get regular diseases*" (Dr Eric Liu)

- The mild arthritis in my left hand is arthritis – it isn't "NET arthritis"



A way of thinking



Living with Cancer

Don't cross the bridge until you come to it

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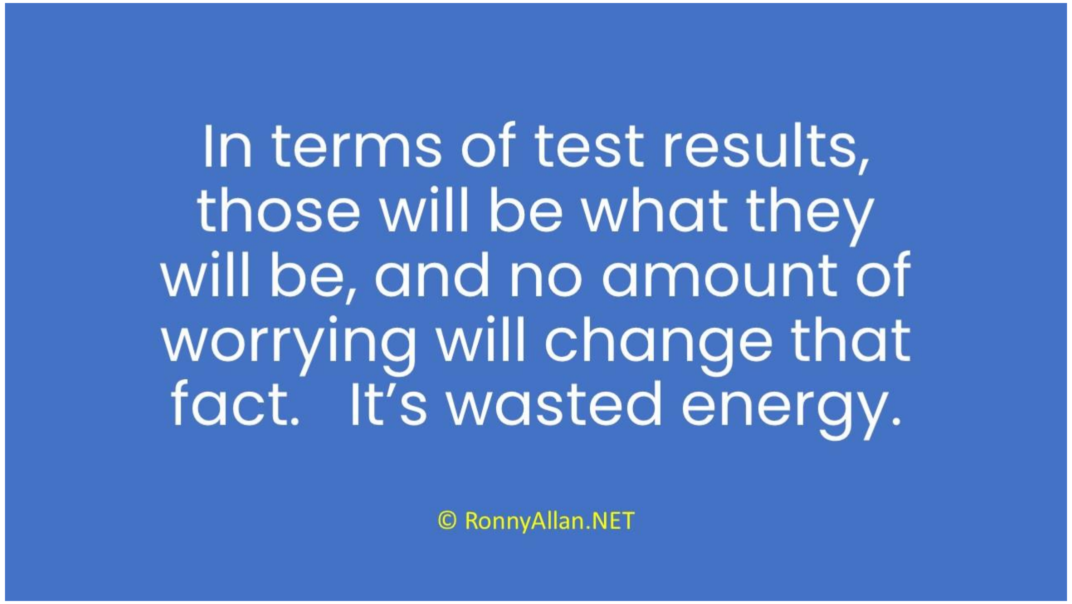

In terms of test results, those will be what they will be, and no amount of worrying will change that fact.   It’s wasted energy.

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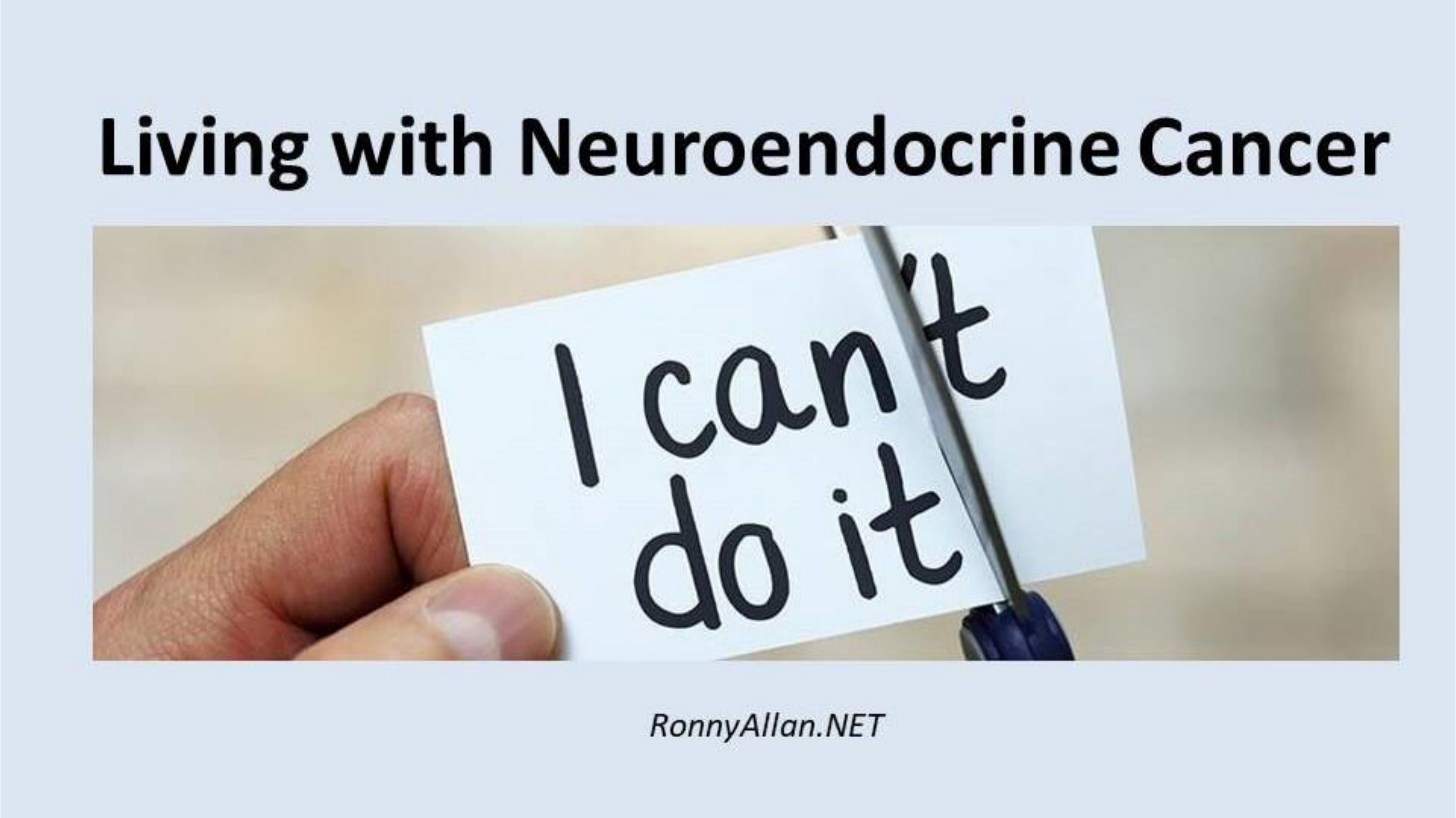
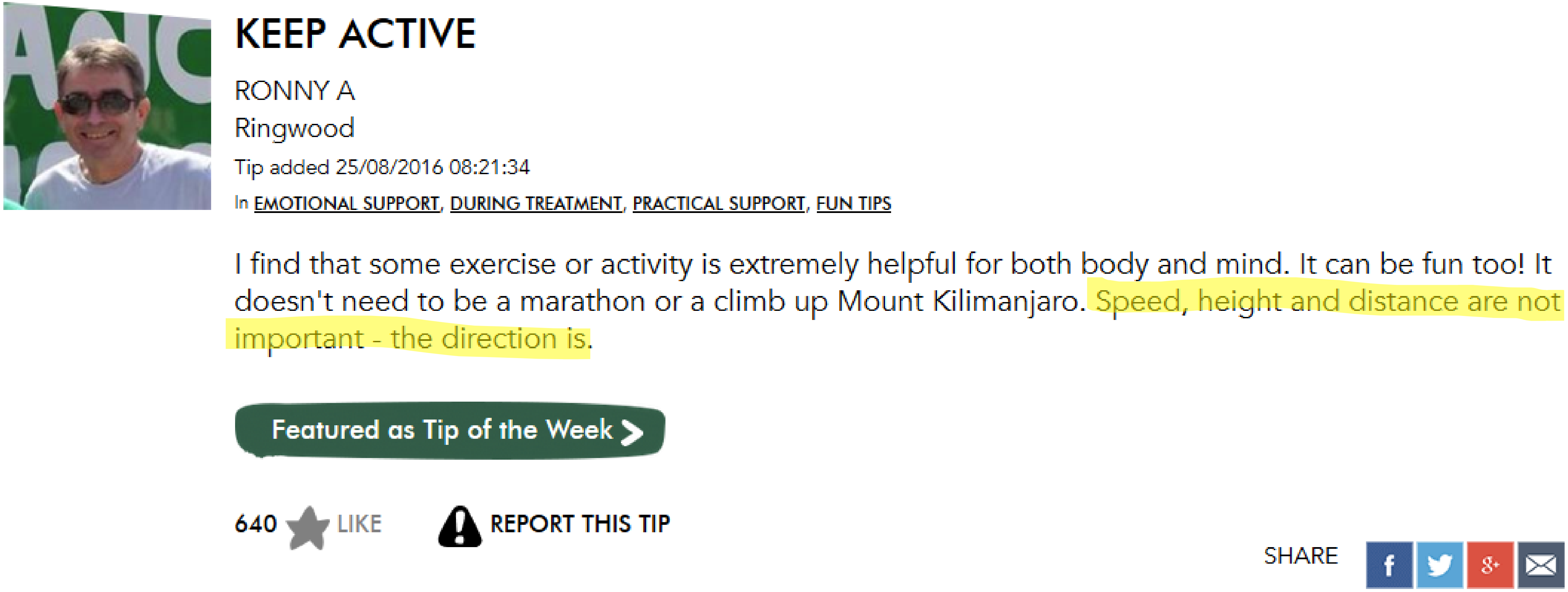
Finding Perspective (….don’t always think the worst)

Living with cancer is also a mental challenge



Sometimes you gotta climb that hill

“….don’t try this at home”



KEEP ACTIVE

RONNY A
Ringwood
Tip added 25/08/2016 08:21:34
In EMOTIONAL SUPPORT, DURING TREATMENT, PRACTICAL SUPPORT, FUN TIPS

I find that some exercise or activity is extremely helpful for both body and mind. It can be fun too! It doesn't need to be a marathon or a climb up Mount Kilimanjaro. Speed, height and distance are not important - the direction is.

A way of thinking (the hill is a metaphor)

- Learn more about the disease,
- Becoming more active (mentally and physically),
- Start a diary,
- Experiment with diet and nutrition (use diary),
- Advocate for yourself and/or others
- Find a hobby,
- etc – you can add more as required,

…. Know your limits.
…. Risks are inevitable.
…. Don't sweat the small stuff.
…. Edit 2022 …Find some nice scenery

I’m still moving on from this

On the Cancer Journey, don't forget to live your life

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(Michael Scott / Unsplash)

I walk (….. and drink tea)

I like a challenge

I enjoy the adventures





Mrs Motivator

Remember, my "hill" is a metaphor

KEEP ACTIVE

RONNY A
Ringwood
Tip added 25/08/2016 08:21:34
In EMOTIONAL SUPPORT, DURING TREATMENT, PRACTICAL SUPPORT, FUN TIPS

I find that some exercise or activity is extremely helpful for both body and mind. It can be fun too! It doesn't need to be a marathon or a climb up Mount Kilimanjaro. Speed, height and distance are not important - the direction is.

Patient stories are important

part of a coping mechanism for many

Ronny Allan

Award Winning blog - https://RonnyAllan.NET/
~1,956,000 views, ~ 944,000 visitors

Award Winning public pages -
https://www.facebook.com/NeuroendocrineCancer.RonnyAllan/
https://www.facebook.com/RonnyAllanBlog
https://www.facebook.com/WNCD10NOV

Accounts:
https://twitter.com/RonnyAllan1
https://twitter.com/Neuroendocrine_

Ronny Allan
Private Facebook group

[Living with Neuroendocrine Cancer – Ronny Allan's Group - https://www.facebook.com/groups/157067628225670/](https://www.facebook.com/groups/157067628225670/)

~7500 members
~70+ countries represented

Proud to have Admins from Canada, US and NZ

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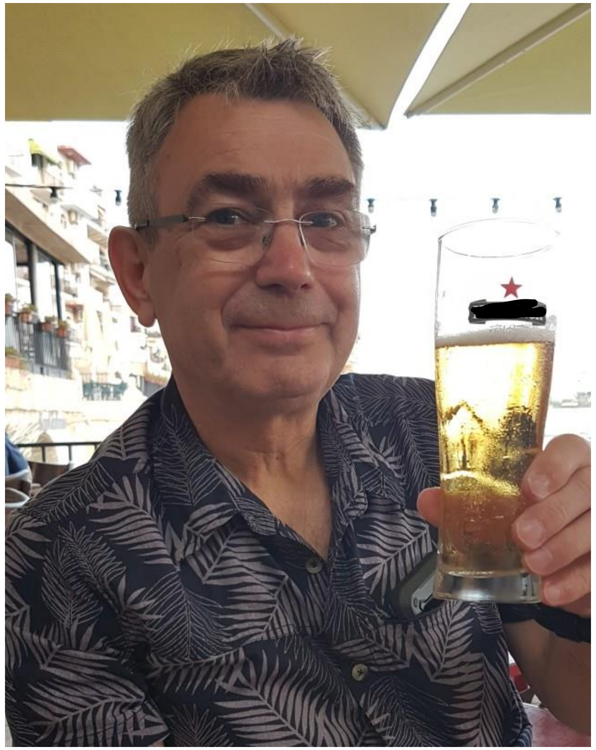
That’s all folks

Thanks for the opportunity to talk today.

Cheers!

Any questions?



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It’s alcohol free!