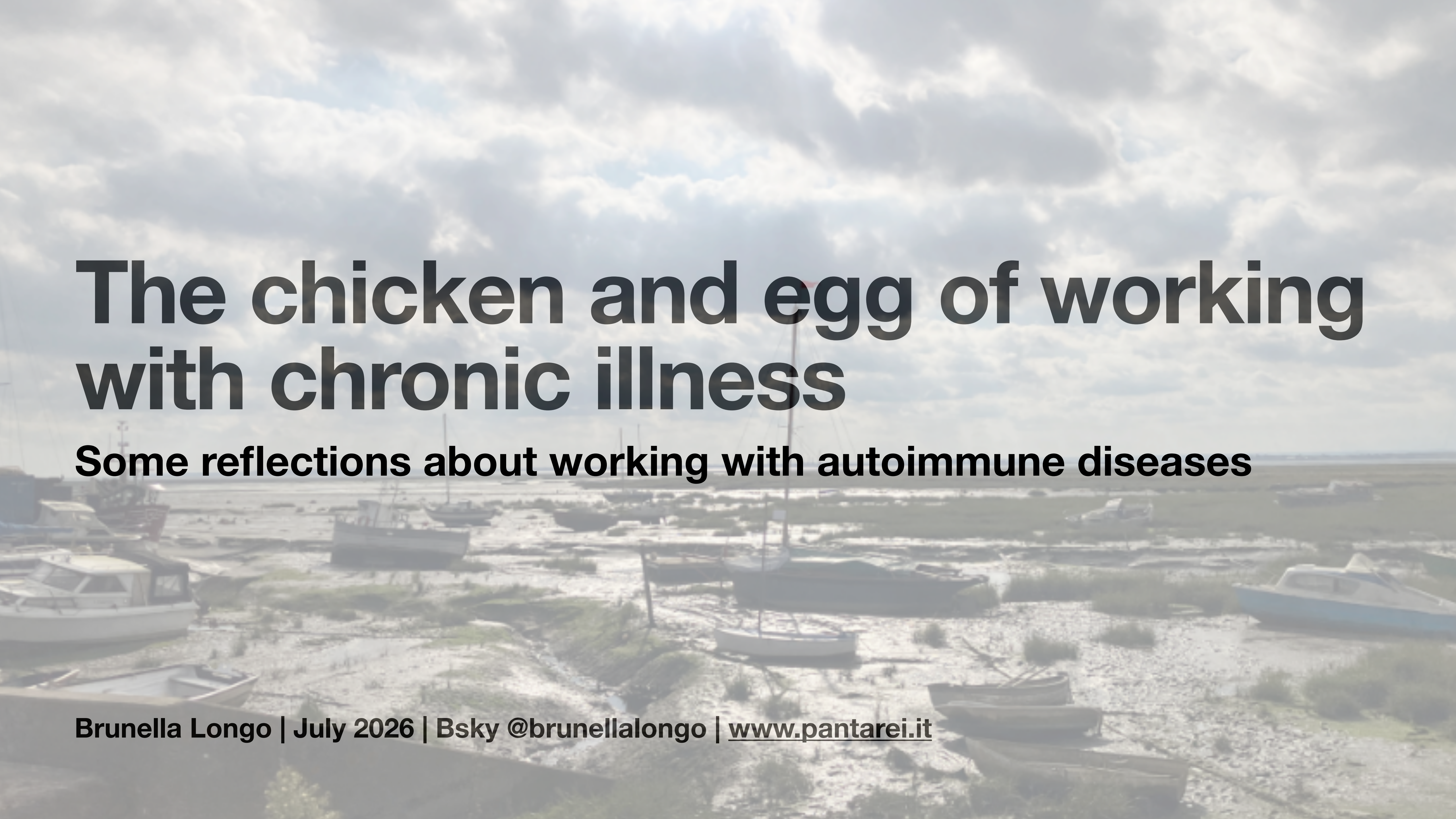




# **The chicken and egg of working with chronic illness**

**Some reflections about working with autoimmune diseases**

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# Before / after diagnosis

(Roughly, but not always, the same as “knowing / not knowing” your disease)

- Understanding symptoms and connecting them into a clinical framework has the potential to change behaviours and personality
  - skills, abilities, interests, commitments, motivation etc become somehow less important
- When we choose to prioritise our longevity we become aware of the consequences of whatever we do, think, feel on health and wellbeing / quality of life
- Knowing early in life our susceptibility to autoimmunity, increased risks of chronic conditions or cancer would make a difference for orienting and informing choices about treatments, self-care, family, education, work, career and lifestyle
- Rapid diagnosis would delay disease progression and preserve quality of life

# Self employed *versus* Employed

## Two worlds apart when working with chronic illnesses

- Overarching distinction: everything else does not count as much as being employed or self-employed (type of work / industry, career and qualifications, experience, skills, motivation, sex, age...)
- Employed? you have a world of established legal protections on your side: workers rights, unions, occupational therapists, culture of entitlements in the welfare benefits systems...
  - Watch out: risk of becoming a burden, poor productivity, isolation, mental health, addictions, entrapment into schemes of adjustments and modified job specifications leading to loss of independence and motivation to self-care
- Self-employed? You are mostly in your own business 'bubble', with fluctuating support from the State and /or from Charities or family
  - Welfare system perversely incentivises more surrender to disease progression in order to give you potential access to more benefits
  - Watch out: risks of suicide, destitution, catastrophic disease progression, early death

# Disease progression *versus* self-care attitude

## Who is the boss in your disease management?

- Even the best treated and mild chronic / autoimmune condition tends inexorably to worsen with age
- Early retirement is precautionary / convenient to ease daily living activities and maintain independence
  - Those who can retire early are in a better position: keep working if you want or can at your pace or volunteer and stay busy with family / community engagements
- Those who cannot retire early have difficult choices to make every day to counterweight disease progression and staying independent as much as possible / as long as possible in spite of lack of resources and increased costs of living
  - Knowledge management for and about autoimmune diseases is of the essence to counterbalance disease progression, maintaining independence and a decent quality of life in older age
  - Money can solve lot of problems too in disease management: never underestimate the importance of asking contracts, payments, the right amount of money, welfare benefits, donations, grants etc although we get a lot of rejections, gaslighting, indifference and emotional abuse for doing so

# Case study

## Lin's VB12 deficiency and Mrs "the life you want" DWP

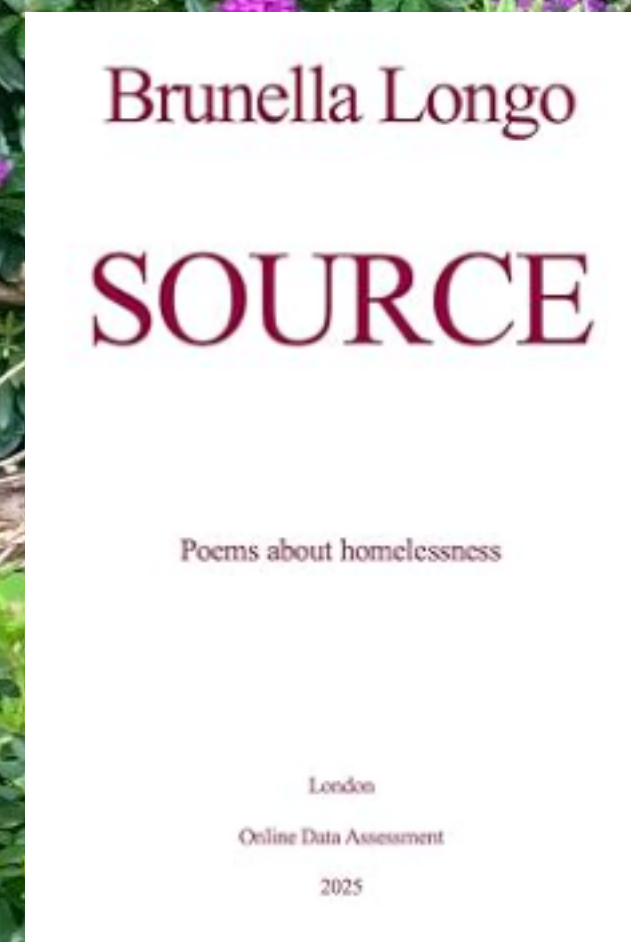
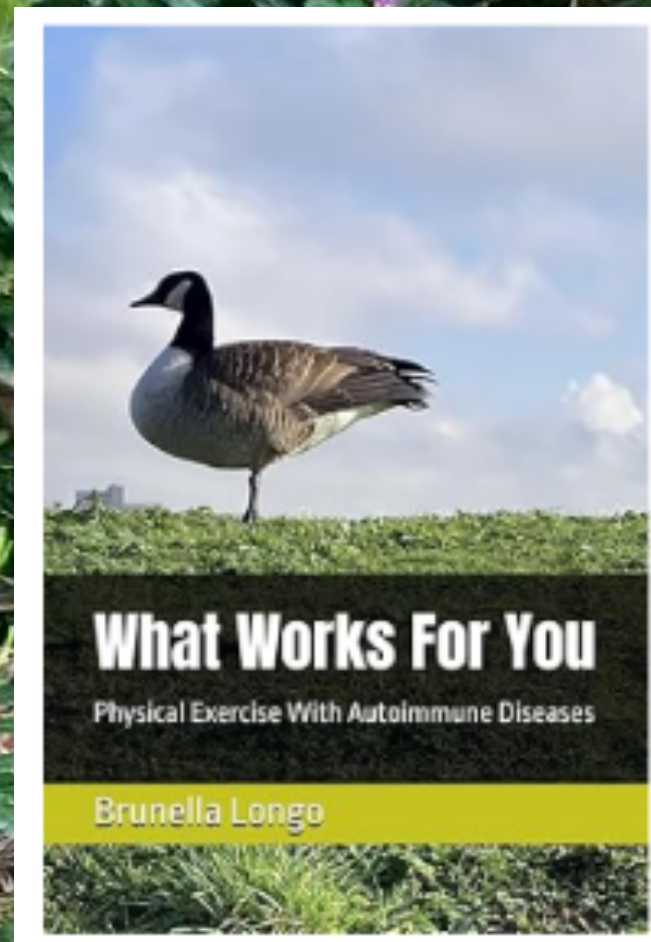
- This is a real case. I met Lin at a private blood tests clinic the year before she committed suicide. As far as I know she did not have clinical depression. She was in her early 60s
- Lin had two or three diagnosis of autoimmune diseases causing fatigue but she was still determined to do freelance work as a translator. She was feeling better taking some immunomodulators prescribed by specialist and also on her own initiative Vitamin B12
- Unfortunately Lin had an additional metabolic problem: she required the form of Vitamin B12 that is only available on prescription (injections). The blood test results said her levels were low but in the normal UK range. She did not have the exact diagnosis for which the UK GP could give her a prescription, even if in USA or Japan her VB12 level and diseases would allow the injections
- Lin could have the injections privately. But she had no spare money being self-employed and on low income. Lin had applied for PIP and working capability assessment to get more money
- Lin's claim failed. She was told by her DWP work coach that there was no medical ground for her claim, she was deemed capable of work and Universal Credit would not support her to "live the life she wanted"

**Thank you!**

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