



Take Stock on autoimmunity

Writing about autoimmune diseases (and beyond)

Bsky | @brunellalongo | Sun 7 Jun 2026

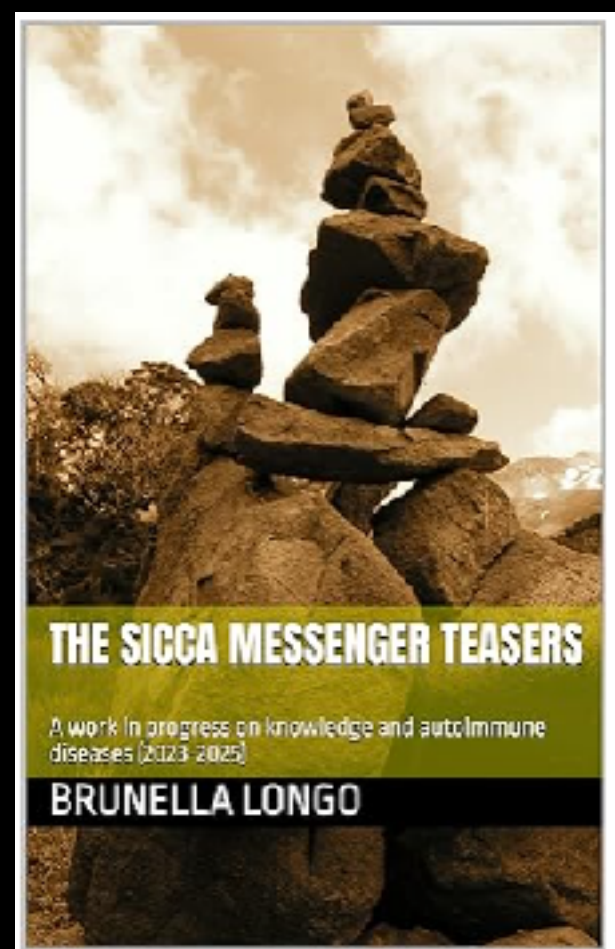
Contents

- Sharing the journey as a work in progress
- Three years into my project...
- It was worthwhile to stop and think what I really wanted to write!
- What we look for when we write about autoimmunity?
- Writing on autoimmunity ...
 - 1. Personal accounts of autoimmune diseases
 - 2. Reflections on own lived experience
 - 3. Clinical literature
- My purpose
- Other factors that may influence writing
- Risk of writing as an “independent writer”
- Preserve the pleasure to write freely and responsibly
- I believe quality of knowledge is part of our well-being and our quality of life.
- Thank you. Useful links and contact details

SHARING THE JOURNEY AS A WORK IN PROGRESS (2023-2025)

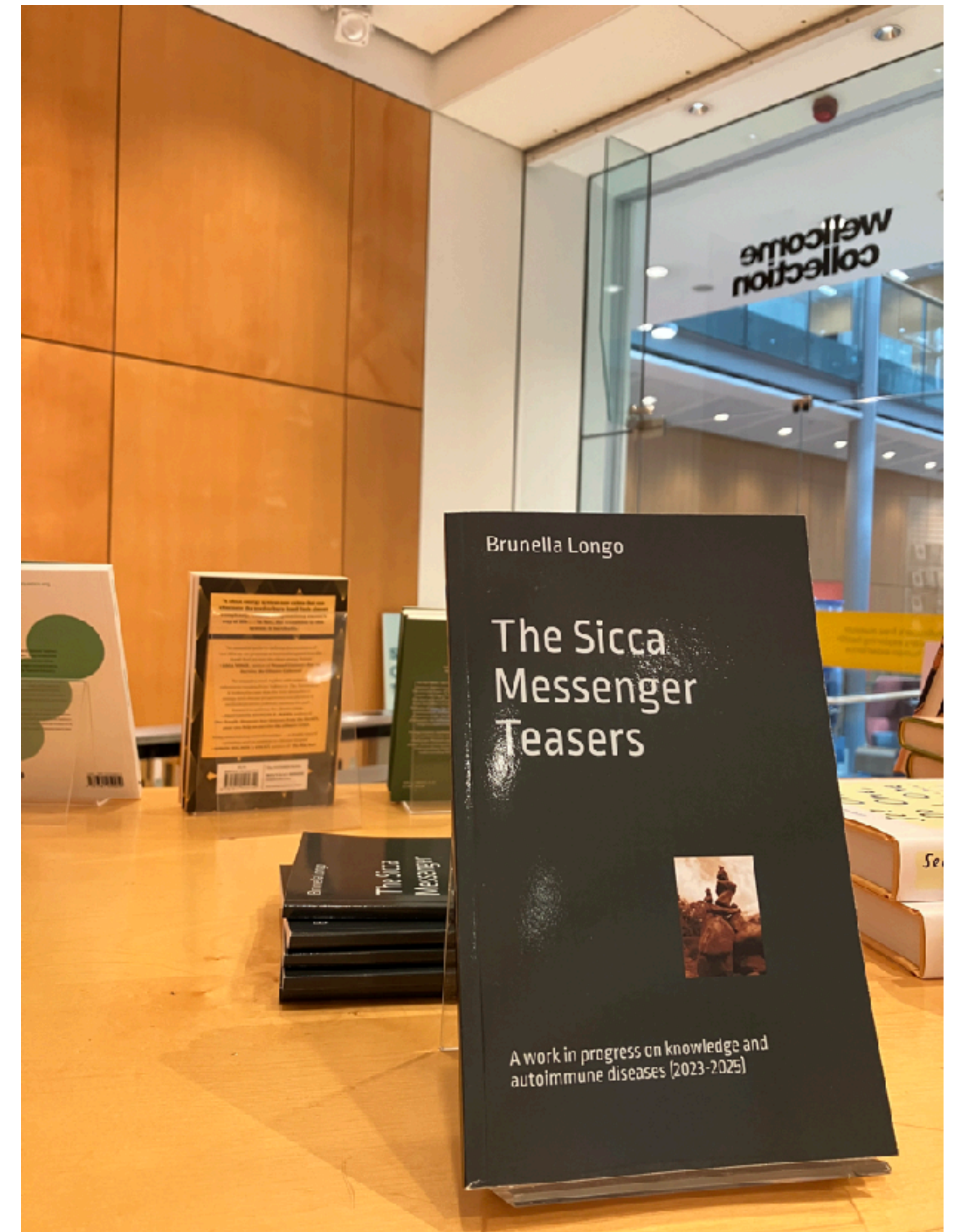
THE SICCA MESSENGER TEASERS

14 ARTICLES (EBOOK + PAPERBACK)



Three years into my project I reached a point of non-return...

- “The Sicca Messenger Teasers” (2025) little book that documents my “grand” work in progress
 - 14 articles that show how I framed the project questions, my own learning, the “silos” existing on knowledge for and about autoimmune diseases...
- I wondered if I really wanted to go ahead writing a series of books I sketched in my mind, structuring contents suitable for fiction and nonfiction formats, and with different styles
- The answer was... YES!
- This little book is on sale online and in selected bookshops in London.
- It was worthwhile to stop and think what I really wanted to write!





"We all need to get the balance right between action and reflection.
With so many distractions it is easy to forget to
pause and take stock"

Queen Elizabeth II

From the inscription seen in the new "Garden for the future" that commemorates Queen Elizabeth II, Regent's Park, London



What we look for when we write about autoimmunity?

Purposes vary enormously with context, role, education, skills...

- Sharing research or data?
- Academic or journalism careers?
- Institutional communication?
- Public engagement with science?
- Advocacy and lobbying?
- Marketing publicity promotions?
- Sense of belonging to / collaboration?

Writing on autoimmunity

Encompasses many types of contents and data

- By different types of authors, medically trained or not, with various levels of education and qualifications, all producing three broad categories of contents:
 1. Personal accounts of autoimmune diseases (mostly covered by generalist and specialised media, podcasts, books and magazines, social media)
 2. Reflections on own lived experience (mostly blogs, books, zines, social media, podcasts, videos)
 3. Clinical literature
- Autoimmune diseases are multifactorial. Contents of type 1 and 2 tend to represent them in holistic ways that means risks of poor scientific value: often subjective knowledge and perception or anecdotic accounts prevail. Contents of the 3rd type may address in depth only one or few aspects, ending paradoxically with... "forgetting" the patient!

Writing on autoimmunity

1. Personal accounts of autoimmune diseases

- Describing symptoms
- Listing signs for diagnosis / differential diagnosis
- Reporting or expressing opinions, including complaints
- Sharing other kind of personal information considered relevant (or not!)
- Describing medical cases

Writing on autoimmunity

2. Reflections on own lived experience

- Rationale for self-care decisions
- Inferences based on symptoms, diet, activities logs (diaries)
- Comparisons among the effectiveness of different medications
- Notes about the progression of the disease, relapses, flares
- Thoughts about guidelines and recommendations in respect of own experience
- Notes about interactions with healthcare professionals and doctors

Writing on autoimmunity

3. Clinical literature

- medical guidance and textbooks
- case studies
- data from longitudinal studies
- registries
- biobanks
- clinical trials

My purpose

Why I write books for “The Sicca Messenger” series

- With “The Sicca Messenger” I have the purpose and ambition to talk in a balanced way about this complex subject. How?
- integrating live experiences of autoimmune diseases, starting with mine, into
- the best up-to-date scientific and comprehensive interdisciplinary knowledge

I have built a library for myself and I share the learning and knowledge I gathered leveraging on my former career in information management and on my writer's passion for information / instructional design.

Other factors that may influence writing

Purpose, style, formats, technologies, values... and the disease!

- Freedom of expression, from censorship and self-censorship: these are essential to unleash creativity
- Publishing and self-publishing processes, standards, systems, glitches can get in the way...
- Vested interests can delay or distort plans
- In sum I believe it is important for me to
 - Declare my goals
 - Pace myself carefully - there are days in which even one hour at the computer is very demanding or unproductive
 - Recognise, explain and even foster the existing diversity of opinions and perspectives, even if I disagree with some
 - Remain open for business: I would very much appreciate sponsorships, grants, funding

The worst that can happen to the world of scientific and medical knowledge is to have an engineered cacophony in which our voice is muted, doubts disappear and only powerful voices are heard

Risk of writing as an “independent writer”

Apart from feeling or being isolated / alone!

- Partial vision on problems and solutions, we need to double our research efforts
- Some people tend to disregard what the independent writer says (even against their own evidence or rationale judgement) because they just do not like the existence of “independent” writers!
- Some believe specific kinds of contents should be created only by certain authors (academics, professional novelists, award winning poets, scientists / researchers, journalists, bloggers) not by independent... pollinators!
- Law, bylaws and ethics very poor in the digital ecosystem powered by AI
- Without editors and publishers: work can be very time consuming, with innumerable revisions
- Lack of access to relevant data (although open science reduced enormously this barrier)

Preserve the pleasure to write freely and responsibly

We all writers and readers...deserve it! Some possibilities:

- Respect and quote your sources and / or your own lived experience at all times
- Unmask / disclose abuses, but take into account that in doing so you increase the risk of incentivising trivial / unwanted interpretations of what you say on social media
- Ask yourself and be prepared to explain why you say what you say, how you came about to your choices of style, content, format, genre, data
- Be transparent on your purpose, clients, influencers, lobbyists, agents, commissions!
- In sum... take stock!

I believe quality of knowledge is part of our well-being and our quality of life.

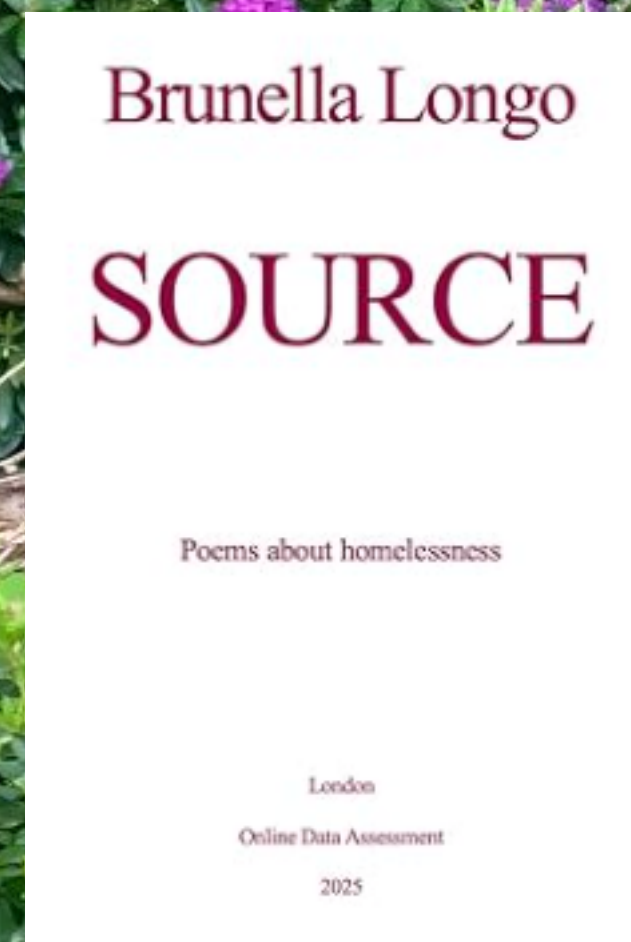
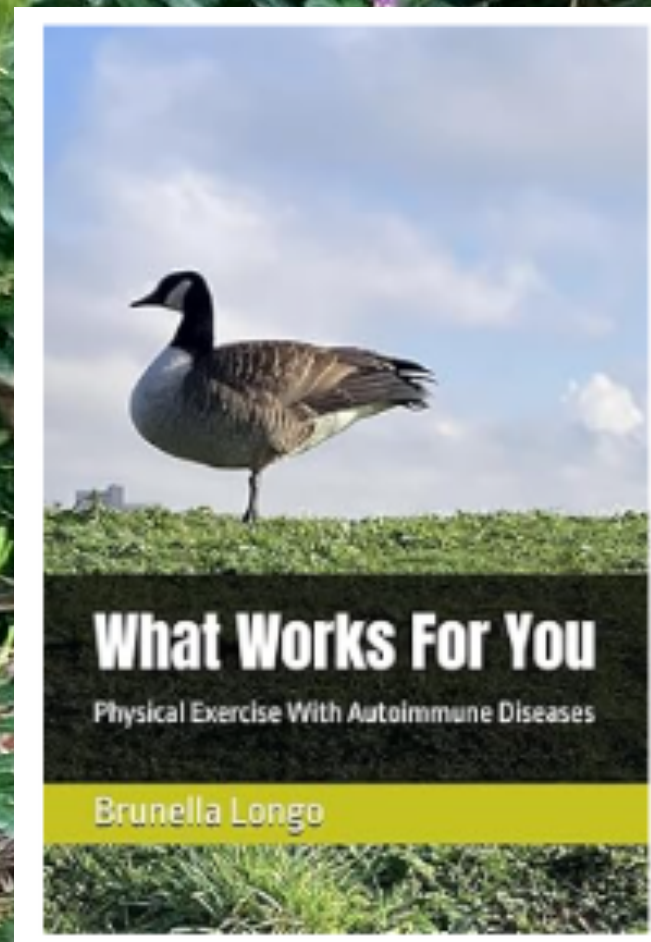
We can feel better and more confident in our self care plans, in our research goals and studies, in how we practice and make decisions if we choose self-reflection and a calm attitude to understand better the contents we are constantly bombarded with, how and why we trust or not trust some people and organisations, the emotional attachment we may have for some sources and the prejudices towards other.

Thank you!

Brunella Longo

icm2re @ gmail.com

Bsky @brunellalongo



Visit www.pantarei.it for my short media bio, updates, links to order the books already published in the “The Sicca Messenger” series!