

Turning STEM into stories

**Why I use fiction and poetry beside nonfiction books
in “The Sicca Messenger” series**

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Focus from an informed interdisciplinary and holistic patient perspective

THE SICCA MESSENGER PROJECT

KNOWLEDGE
MANAGEMENT &
AUTOIMMUNE
DISEASES



“I was soon confronted with the finiteness of the non-fiction world, with the challenge of integrating not only different bodies of knowledge, insight from different disciplines, medical protocols, educational curricula and standards of care established during different historical periods, but also the subjective understanding of these conditions within patients associations, communities of practice, pharmaceutical companies, social media and my own subjective knowledge.”

How to talk about aetiology?

The most avoided topic in conversations doctors-patients!

- The current most accepted discourse says autoimmune diseases are “multifactorial” but inconclusive debates and studies continue...
- Many researchers and the pharmaceutical industry continue to investigate single ideas and hypotheses, supported by some studies and contradicted by others: viral and bacterial infections, toxins, the hygiene hypothesis, the genetic mutations, the damage theory...
- Patients continue to wonder and ask themselves what does it cause the immune system to be offended in the first place, and to remain permanently damaged up to the point that in the long term it cannot revert to a normal function, not even with immunomodulators or new therapies...

Three years into my project

Ideas theories and data that stacked up...

- Why women?
 - Hormonal imbalances and women health overlooked
- Overlapping diseases?
 - SNA used in computational genomics showed polygenic nature
- Immune light?
 - Polly Matzinger's "danger theory" revisited (Nature 2024)
 - Urgent call to action for improved understanding (article by FW Miller 2023)
- New overwhelming data evidence from biobanks and authoritative clinical views
 - Adverse Childhood Experiences (ACEs) and Trauma / Critical incidents / Injuries in adulthood

Trauma in adulthood

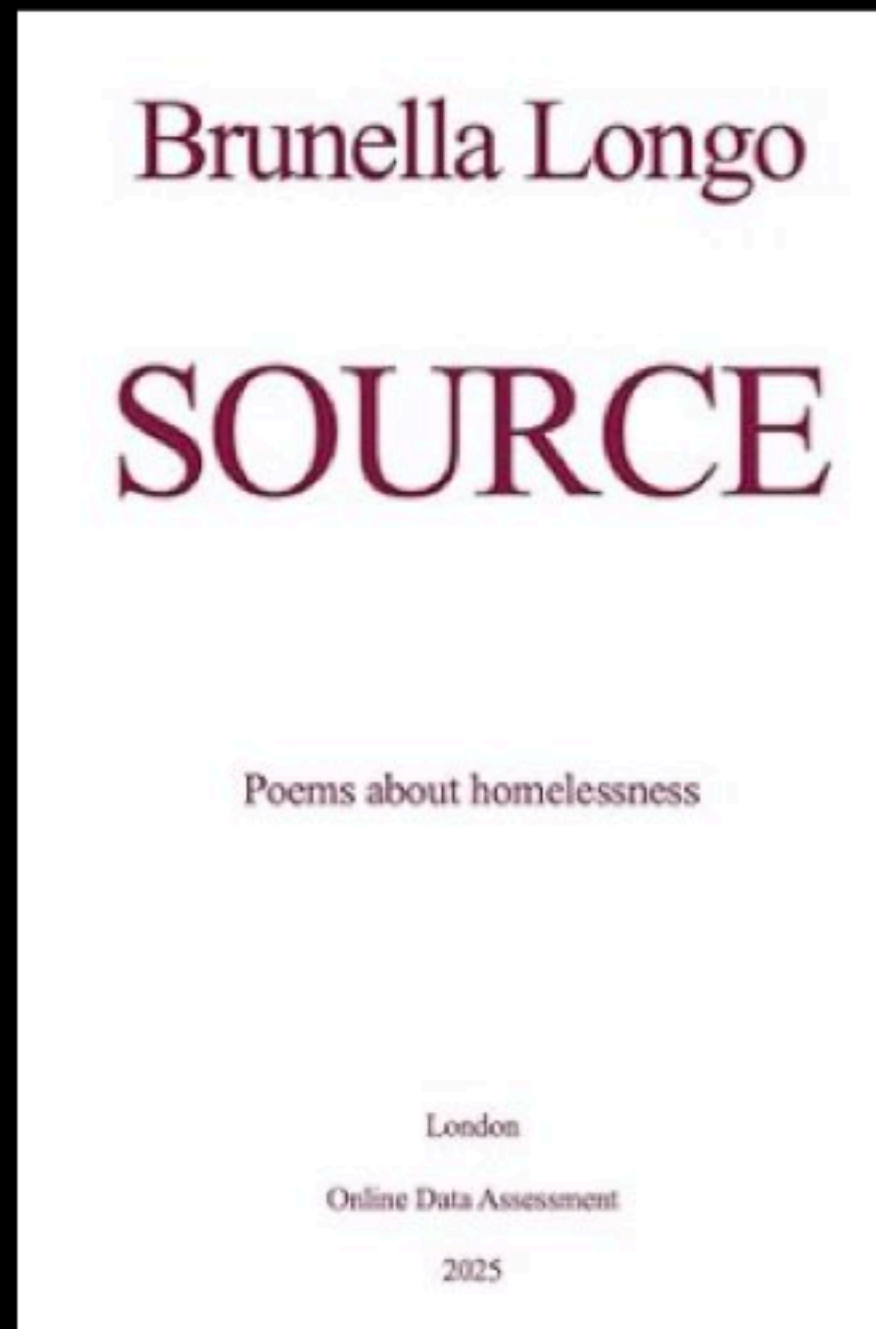
Authoritative clinical views

- I was diagnosed with Sjögren's between 2016 and 2017 while I was recovering from a protracted period of homelessness for the third time in less than 10 years: destitution, isolation, the loss of all my savings, my professional career, friends and family, my dog and all my belongings...

“Prior to disease onset, patients with Sjögren's disease experience major stressful life events with which they cannot cope adequately”
(Harrison's Principles of Internal Medicine, 21st edition, 2022, p. 2788)

USING POETRY TO TALK ABOUT TRAUMA IN ADULthood

SOURCE: POEMS ABOUT HOMELESSNESS



Source: Poems About Homelessness (2025)

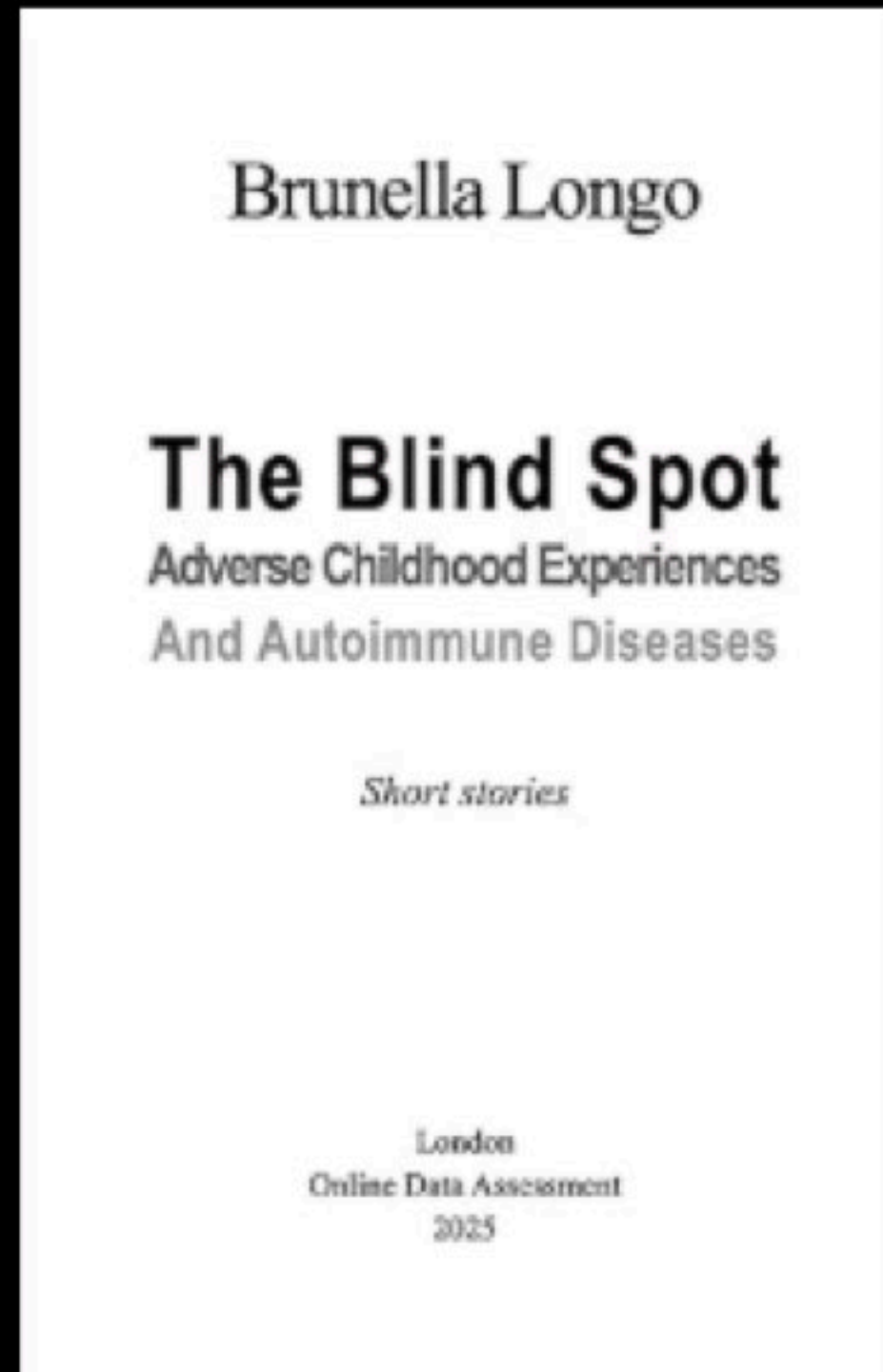
Social testimony and healing words in 45 poems

- “Legal” persecutory, repeated ‘no fault’ evictions through Section 21 notices were an exploitation of the former Landlord and Tenant legislation, the legal routes to homelessness, destitution, coercion and economic violence, also intertwined with and obfuscated by other factors like planning requirements / enforcement or astute scams on defective premises: Section 21 evictions are now abolished (since 1st May 2026)
- The power of Asclepius came to mind suggesting to tell my story through these healing words
- Postface + essential bibliography about housing as a social determinant of health

USING FICTION TO TALK ABOUT THE CAUSES: THEORIES, DATA, RESEARCH

THE BLIND SPOT: ADVERSE CHILDHOOD
EXPERIENCES AND AUTOIMMUNE DISEASES

SHORT STORIES



Scientific evidence about ACEs and trauma

“As of 2025 there is compelling consensus and scientific evidence worldwide that we are born with some innate, polygenic predisposition to autoimmune diseases, also called genetic susceptibility, but we actually develop an active disease only if we go through highly variable, subjective experiences of injury, loss, trauma, abuse, damage to the body and the mind”.

- 2009 data of over 15000 adults
- 2025 data about 108,915 adults (women)

“Adverse childhood experiences could be seen as a lasting sign of "diathesis" (a medical term for vulnerability or predisposition) that makes some individuals more likely to be penalised in life by harmful stressors, compared to those who do not experience such burden earlier in life.”

I gave all my symptoms to others!

Fictional characters less boring and easier to sympathise with

- Each story contains something from my own lived experience and biography in various proportions
- Each story hybridised with nonfiction insertions for the purpose of sharing reliable scientific information and references to medical studies
- Each story has “a spark of trust in our sentient nature, in our ability to subjective and objective critical knowledge”

“The protagonists have touched the limits of their tolerance to stress and impairments caused by autoimmunity: yet, they do want to get on with their lives, with the adjustments they need, no matter the conditions”

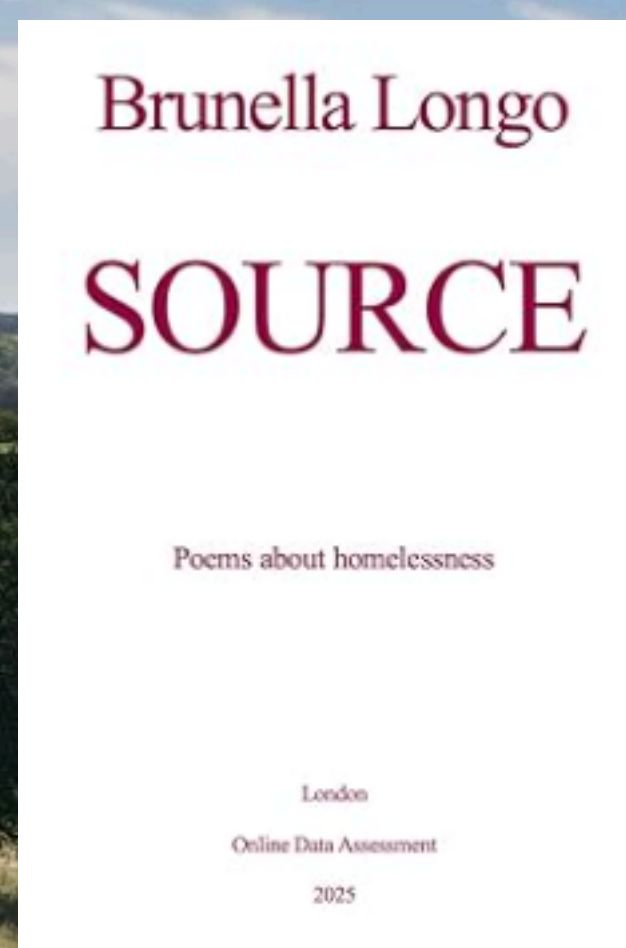
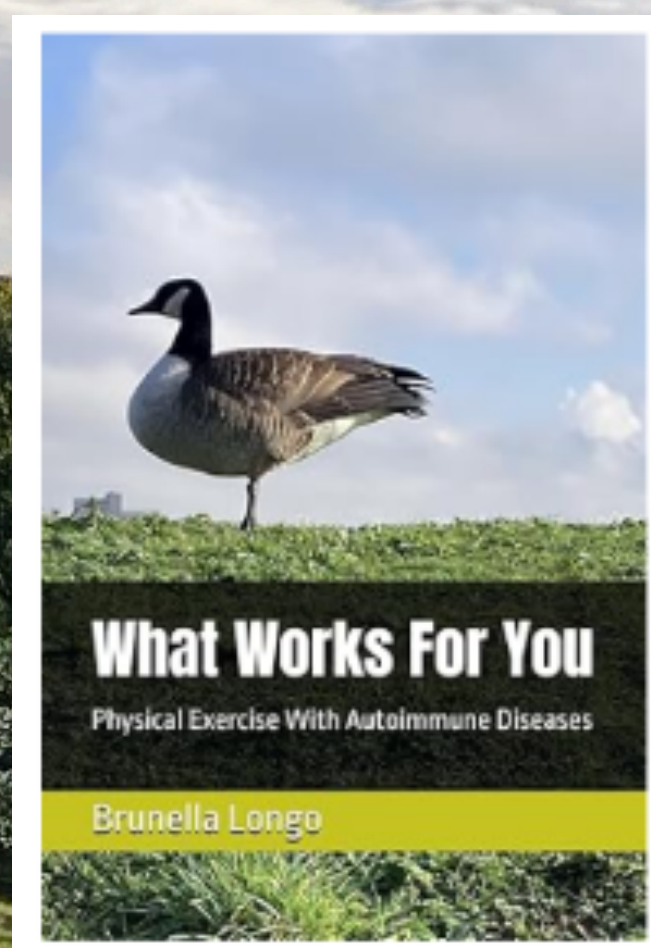
Themes I could weave within a fiction format

Showing the powerful influence of ...

- Family contexts
- Workplace culture and organisation
- Trends in medicine and expectations in healthcare
- “Silos” specialisms unfit to deal with systemic conditions
- Evolving medical ideas, criteria for diagnosis and clinical trials, guidelines...

In a non-fiction format I could not document or explain these contexts that are so important for quality of life and for disease management

“I am among those who believe that subjective knowledge represents a valuable contribution to the collective understanding of autoimmune diseases”.



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

Thank you!

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