

**‘Spirit’**

# Many Meanings of 'Spirit'

□ *Spiritus – a breath*

A ghost

A drink

A mysterious transport

Resilience

A message from God

Energy

A wind

Temperament

Loyalty

Attitude

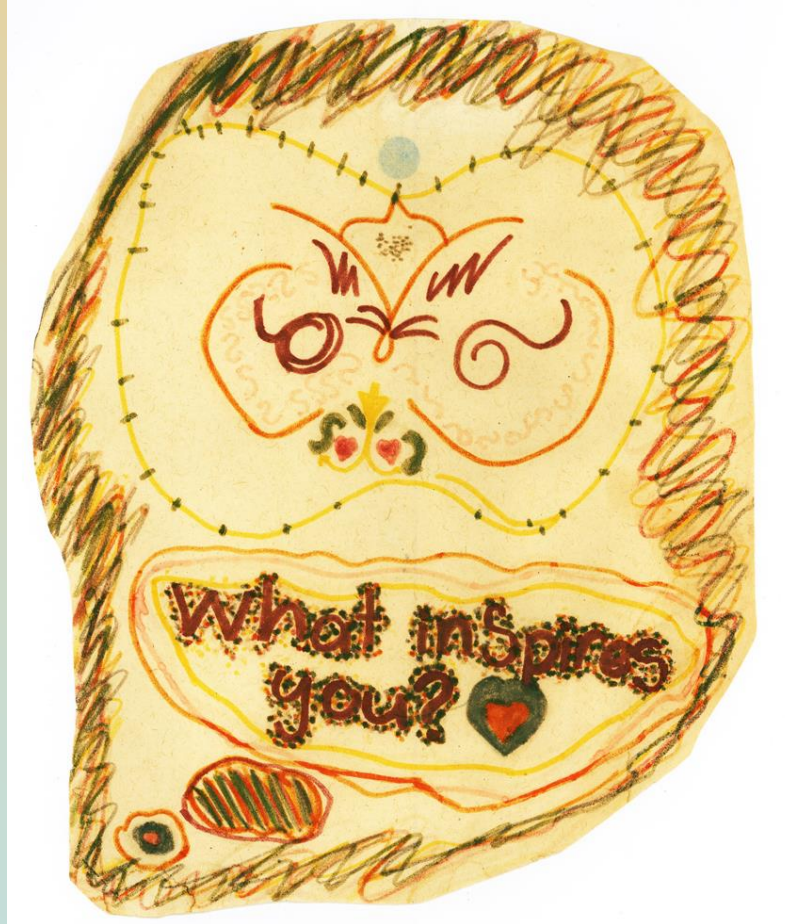
Deeper meaning

Soul

Dead person

An inspiration

# “What Inspires You?”



Drawing by Carolyn Maddocks,  
aged 7

Three themes regarding Spirit:

Spirit in Papua

Spirit in Cancer

Spirit in Infectious disease

# A View from Papua - a village where I lived for 6 years

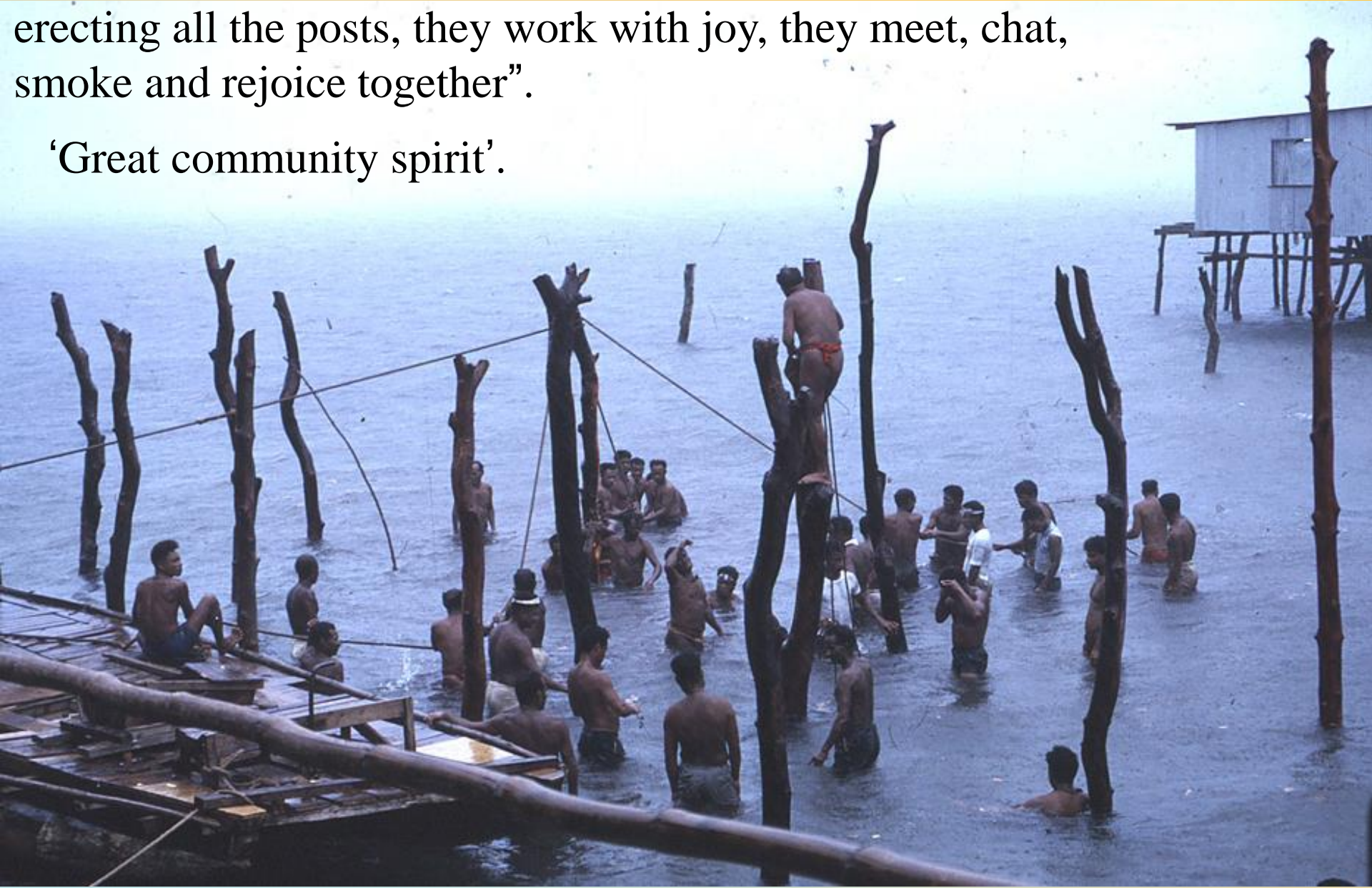


Pari is a village of the Motu people, their forefathers the first to meet Captain Moresby, in Fairfax Harbour, 1872.  
The village in 1972, our house marked X



From an interview, 1964: “On the day of the putting up of the posts all the village will meet, and make a clean sweep of erecting all the posts, they work with joy, they meet, chat, smoke and rejoice together”.

‘Great community spirit’.







A *vagoma* is first put into the place for the erection of the post, then a post is stood up and worked in.





Preparing a new garden

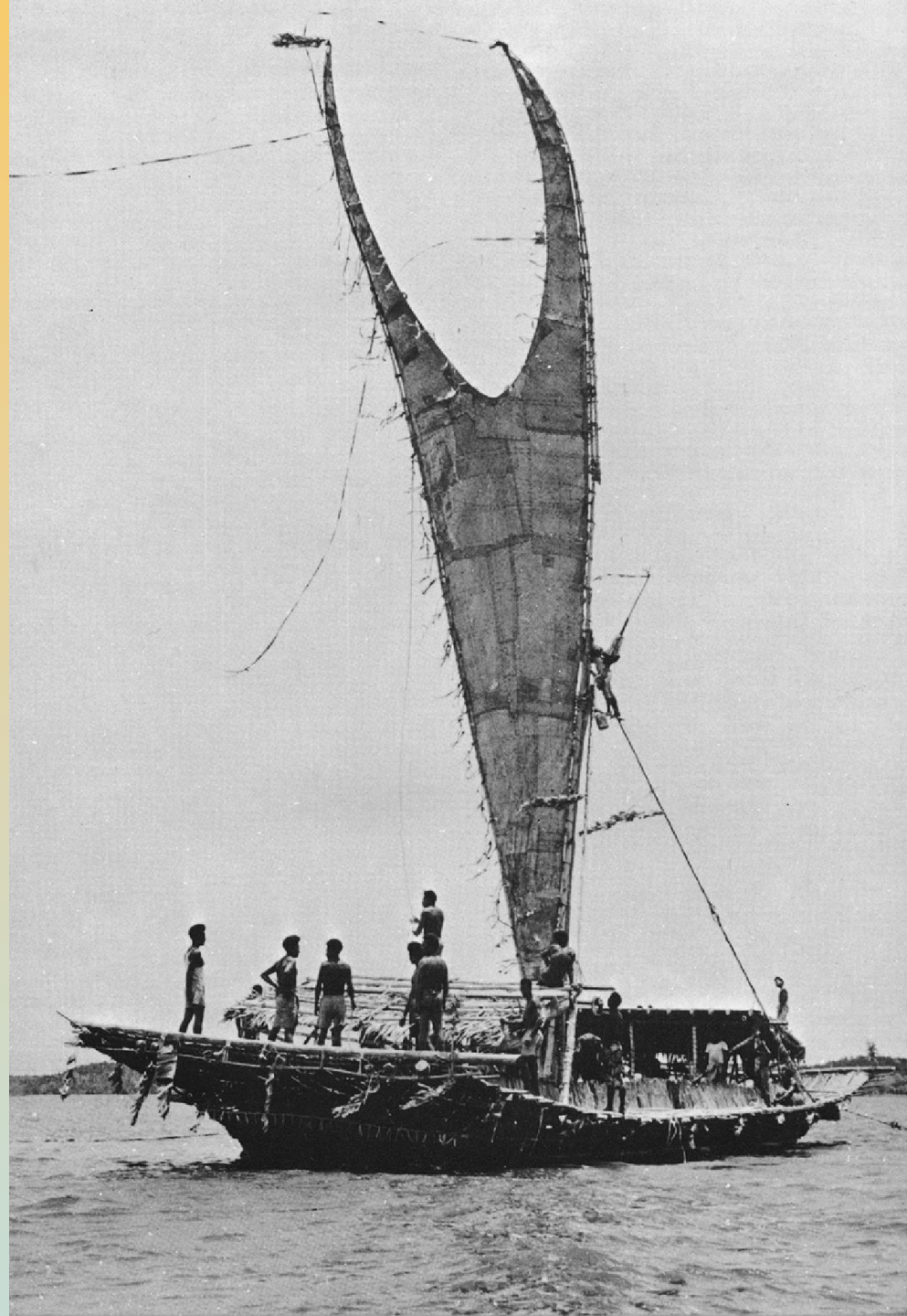


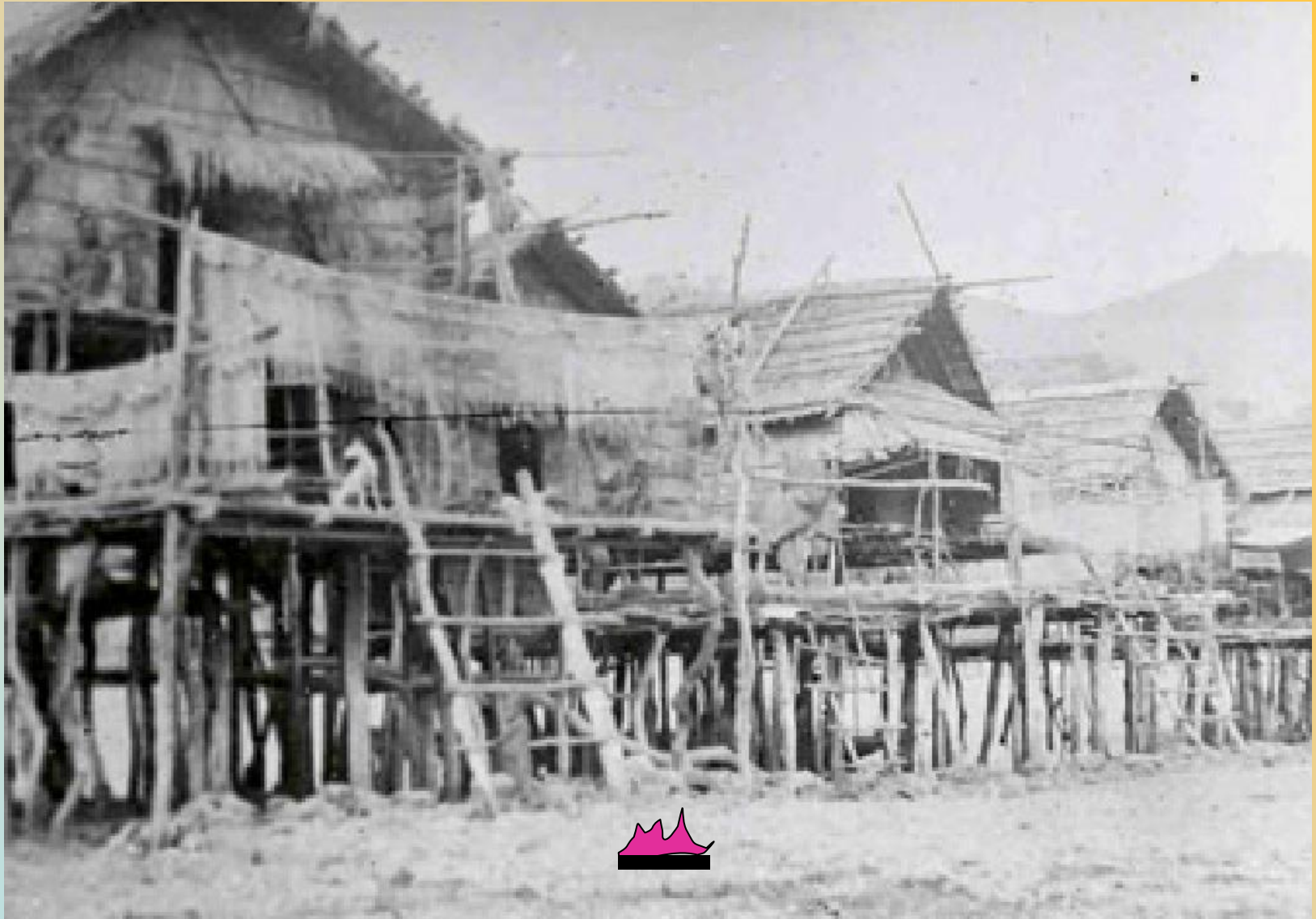
Trapping a school of small fish



A Hiri expedition to the Gulf of Papua entailed months of preparation and up to thirty men away for over two months on a dangerous voyage.

A spirit of adventure





As a first step in planning a Hiri, the Badi Tauna (captain) would light a small fire by his steps.





Turia feast display on  
a *dubu* platform at Pari  
100 years ago

To effect a turia feast  
will take months of  
preparation by all the  
extended family,  
ensuring that garden  
produce is adequate for  
a fine display on the  
dubu, and generous  
distribution to win  
status.

Spirit of  
□ ambition?





A spirit of cooperation

Kidukidu - the annual tuna fishing - remembering the legend of Pari woman who gave birth to 5 tuna fish.

Much ritual and preparation to ensure a good catch.



# The power of Ancestor Spirits in the village

They stay around

They interfere

They watch what is done

They can be known in dreams,  
in solemn gatherings

They disapprove when correct behaviour  
is not followed

They punish with misfortune or sickness.





The Force of Change - looking from Pari over Taurama Barracks to Bootless Bay.



# Change

Rapid population increase

Intrusion by foreigners

- destruction of reefs
- stealing from gardens
- gate-crashing of events

Need for cash

- school fees
- store foods
- bride price payments
- church contributions

City violence, fear of gangs

Widespread corruption

The Ancestor Spirits have lost their power

There is a Spirit of Despair

# Spirit in Cancer

A threat to the spirit:

anger, fear, hope, anxiety (= death?).

Calls forth a fighting spirit? (But Susan Sontag)

Recurrence of cancer is a bigger threat than  
First diagnosis - I am not 'winning'

What place for a spirit of acceptance?

Relaxation, peace of mind more effective than 'fight'

What hope when there is 'no hope'.



## Spirit in Infection

The Flinders Ranges of South Australia are home to many thousands of feral goats. They are regularly rounded up by Helicopter and slaughtered; some find their way to abattoirs and are processed for pet food







Around 1980, I became interested in the health of meat workers and was approached by the abattoir at Gepps Cross to assist in the care of individuals who had been infected by Q fever,

Q fever is an infection endemic in South Australia's feral goats. It spread through droplets, stays in dust in cattle yards, is present in high concentrations in placenta of feral goats.

Infection may therefore be picked up outside in the yards or within the works where pressure hoses raise droplets around the slaughter areas.

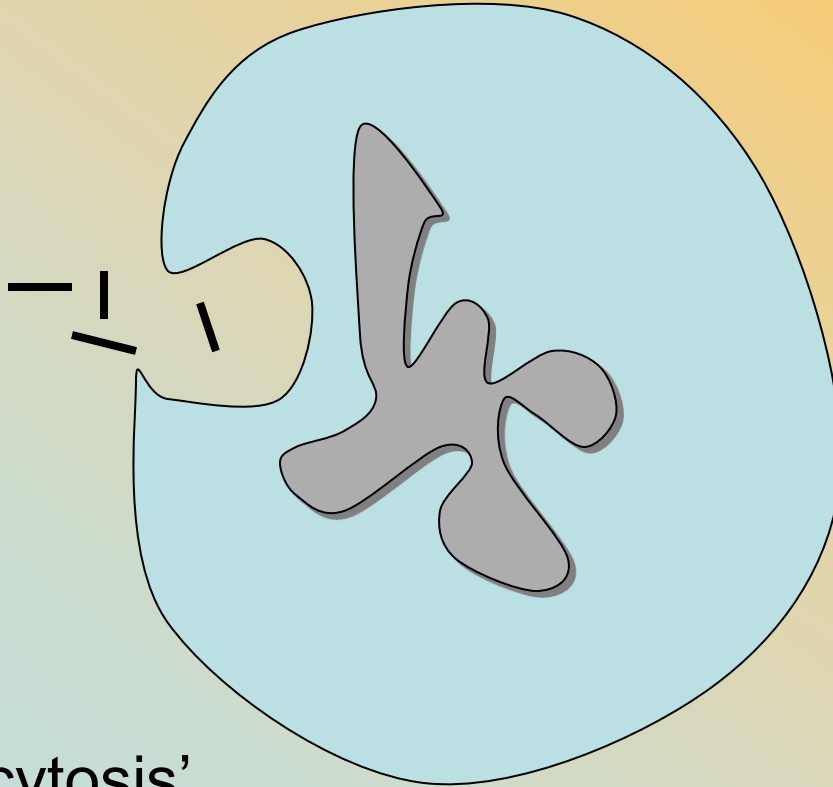


The causative organism of Q fever, *Coxiella burnetii*, is a minute intra-cellular organism; It can modify the action of defending white cells that seek to engulf it and enclosing it in pockets in the cell.

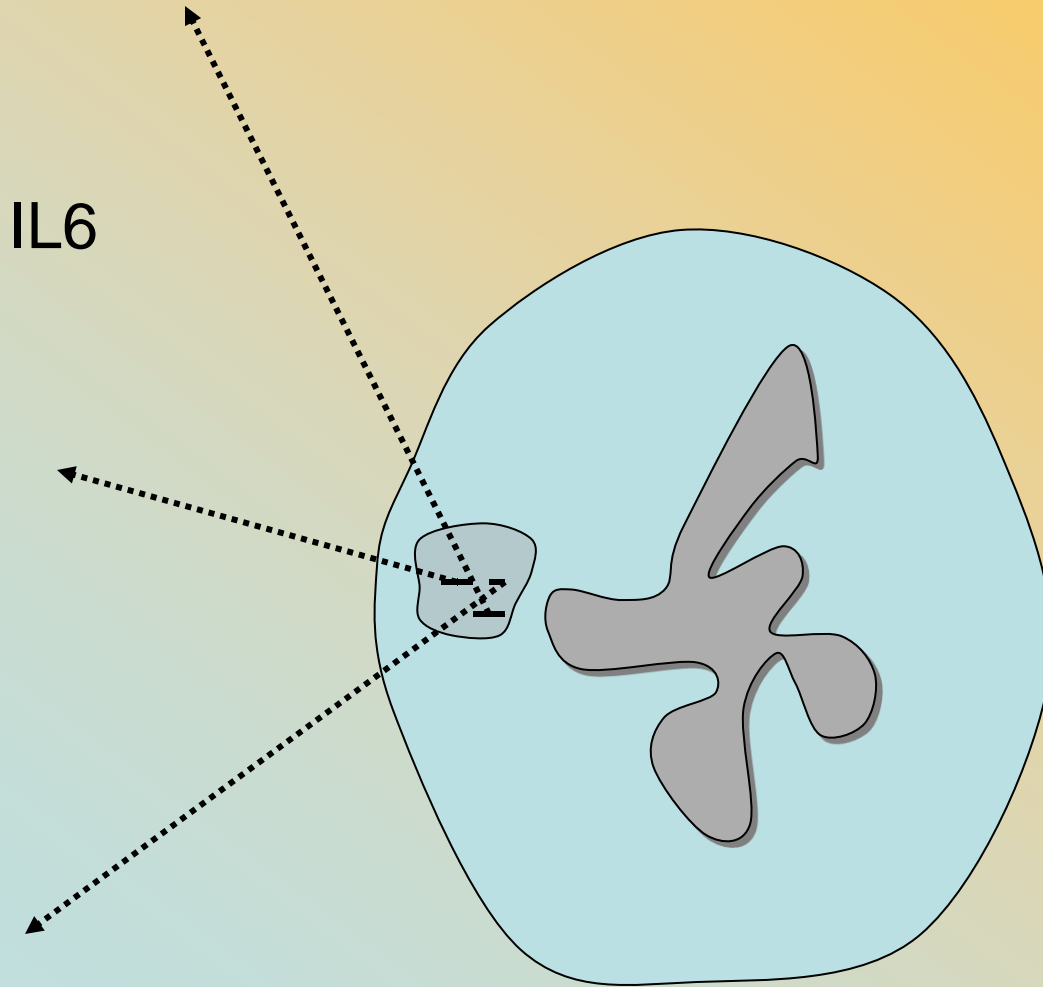
It has the capacity to change those pockets forming spaces where growth of the organisms is supported.

It does not kill the cell nor is it eliminated by the white cell; fragments of the *Coxiella* persist, and it appears that this can lead to an impaired immune response and a long-lasting fatigue syndrome

White cell engulfs  
the invading  
organisms



‘Phagocytosis’



Organisms are taken into the cell and usually destroyed. For some, conditions, however, fragments survive and continue to stimulate immune responses - eg IL6

The result is a continuation of discomfort - eg. Post-Q fever syndrome



# Characteristics of Post Q Fever Fatigue Syndrome

- Severe incapacitating fatigue
- Pain, but no swelling, in joints and pain in muscles
- Frequent headache
- Profuse night sweats with no fever
- Depression, impaired sleep, anger, low libido
- Worse with use of alcohol

Low levels of circulating antibody could be found indicating past infection by Q fever, but no active infection could be demonstrated. Doctors were puzzled, and the employer was inclined to claim that the worker was malingering.

My belief in the validity of the QFS stories was strengthened by the experience of two other patients.

Two insurance executives made a visit to the meat works in the course of an assessment of insurance needs.

19 days later (the incubation period of Q fever) they both suffered a flu-like illness, were off work for a few days and returned to work. But both found that they were constantly fatigued, also had sweats, muscle aches and elements of depression.

These were not malingerers; they were desperate to return to work, but felt the daily round a great strain. Over several weeks one recovered, the other took many months.

Professor Klimas:

“Look at the studies of many patients - and they tell you the same. It is not difficult. Immune findings in CFS is proved. It is not controversial, it is not an hypothesis. There is immune activation in dysfunctional cells and a significant dysfunction of the immune system. I have no difficulty saying with great certainty that the immune system in CFS is not working as it should.”



The working hypothesis that:

‘Viable coxiella or their cell components, including antigens, persist in the Q fever patient, and, in a minority and over a period, hyper-stimulate and distort the type 4 CMI response, generating cytokine dysregulation and contributing to the QFS state’

*Has now achieved considerable proof*

Why am I telling you about Q fever?

It may have some links with Post polio syndrome

Persistent virus infection of muscle in Postviral Fatigue Syndromes (PVS).

British Medical Bulletin 1991, Vol 47, No 4, 852-851

Muscle biopsy samples from a series of highly selected patients suffering from chronic muscle fatiguability following a viral infection found enteroviral RNA in 24% of samples. Persisting virus is defective in control of RNA replication . .

‘It is possible that immune mediators such as interferons or interleukins are released, resulting in the further symptoms experienced by some PVFS patients’.

## *New treatments might become possible*

“The understanding of the abnormalities occurring at molecular level in fatigue syndromes is essential to develop new therapies intended for their correction. . .

The use of immunotherapy, immunomodulators and antiviral and anti-biotherapy will gain a prominent place in the therapeutic arsenal and strategies aimed at fighting the syndrome . . In the not so distant time these will become accepted standards’.

De Meirleir et al;. Chronic Fatigue Syndrome: A biological approach from laboratory to patient care. Pp 265-284, Chronic Fatigue Syndrome.CRC Press, 2002



## **Symptoms of the late effects of polio include:**

- unaccustomed fatigue unrelated to activity
- decreased strength and endurance
- pain in muscles and/or joints
- an inability to stay alert
- weakness and muscle atrophy
- muscle and joint pain
- muscle spasms/twitching
- respiratory and sleep problems
- swallowing or speaking difficulties

----- Very similar to other fatigue syndromes

Most often, however, polio survivors start to experience gradual new weakening in muscles that were previously affected by the polio infection.

# Post-polio is different in many ways

Late onset, relates to previously affected muscles

Progresses

Pathology? - over-extended motor units cause stress to the motor neurons, which over time lose the ability to maintain the increased work demands.

This results in the slow deterioration of the neurons, which leads to loss of muscle strength.

BUT some similarities in symptoms and in pathology

Especially the immune response area - eg. elevated IL6

ALSO: Similarities in effects on 'Spirit





# Polio as a Threat to the Spirit

Paralyses/pain in limbs, back, respiratory muscles  
Unforeseen, unpredictable onset  
Often in childhood  
Prolonged course  
Multiple discomforts from illness  
Multiple discomforts from treatments  
Uncertain prognosis

## Why Me?



# Post-Polio as a Threat to the Spirit

A debilitating disease of prolonged duration

Occurs sometimes a long time after an infection  
so that any relationship is unclear, and not  
accepted

No specific pathology can be discovered

No treatment seems to help

It is easy to conclude that this is 'all psychological'

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# What Assists such Threats to the Spirit?

- Being believed
- Learning to accept the reality of the condition yourself
- Finding positive things to engage in and enjoy
- Learning more about possible pathologies
- Meeting other similar patients and sharing stories
- Being open to different treatments and finding for yourself what gives some assistance:
  - physical,
  - psychological,
  - alternative,
  - religious,
  - spiritual.

# Aids for the Spirit

Relationship - the magic of 'two'

Ritual - reliable, familiar

Silence - meditation, relaxation,

Company - compatible, understanding, non-judgmental

Place - known, safe, in control

Music - rhythm, creativity, memory (hymns etc)

Literature - words, poems, familiar passages (scripture)

Beauty - of place, of person, of feelings (awe)

Thankyou for your attention

May your spirit remain buoyant and strong so that you face the future with confidence and respond readily to the love around you.

