

Seminar

# Illness Identities



Steve Midgley

# Illness Identities

*Healthy and Unhealthy responses to medical diagnoses*

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# An opening discussion

- Suppose you have been experiencing fatigue for four months – the tiredness is increasingly limiting normal activities.
- You visit your GP who arranges a range of tests and then you return for the results

# Five scenarios

1. A virus is identified; fatigue will last between 6 months and a year; no treatment will make any difference.
2. All tests are normal; no diagnosis; monitor, wait and see
3. Underactive thyroid; replacement thyroid hormone will resolve your fatigue
4. You have Fibromyalgia – treated with pain relief and graduated exercise.
5. All tests are normal; fatigue is linked to external stressors; recommend you see a counsellor or psychiatrist.

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# Discuss

- Which of these diagnoses would you prefer to get?
- Can you put them in order of preference?
- What is it that makes one diagnosis preferable to another?

# Positive aspects of a diagnosis

- Validation
- Understanding
- Treatment
- Prognosis

# Five scenarios

- 1. Validation & understanding** – you have a virus and it's known to cause fatigue
2. All tests are normal; no diagnosis; monitor, wait and see
3. Underactive thyroid; replacement thyroid hormone will resolve your fatigue
4. You have Fibromyalgia – treated with pain relief and graduated exercise.
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# Five scenarios

1. **Validation & understanding** – you have a virus and it's known to cause fatigue
2. **No validation** – nothing has been found
3. Underactive thyroid; replacement thyroid hormone will resolve your fatigue
4. You have Fibromyalgia – treated with pain relief and graduated exercise.
5. All tests are normal; fatigue is linked to external stressors; recommend you see a counsellor or psychiatrist.

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# Five scenarios

1. **Validation & understanding** – you have a virus and it's known to cause fatigue
2. **No validation** – nothing has been found
3. **Validation, understanding, treatment & prognosis!**  
thyroid problem that is treatable and will improve
4. You have Fibromyalgia – treated with pain relief and graduated exercise.
5. All tests are normal; fatigue is linked to external stressors; recommend you see a counsellor or psychiatrist.

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# Five scenarios

1. **Validation & understanding** – you have a virus and it's known to cause fatigue
2. **No validation** – nothing has been found
3. **Validation, understanding, treatment & prognosis!** thyroid problem that is treatable and will improve
4. **Validation (but no understanding); treatment (but no prognosis);** a disputed medical diagnosis
5. All tests are normal; fatigue is linked to external stressors; recommend you see a counsellor or psychiatrist.

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# Five scenarios

1. **Validation & understanding** – you have a virus and it's known to cause fatigue
2. **No validation** – nothing has been found
3. **Validation, understanding, treatment & prognosis!** thyroid problem that is treatable and will improve
4. **Validation (but no understanding); treatment (but no prognosis);** a disputed medical diagnosis
5. Psychosomatic disorder; **rarely validating; hard to understand; treatment but no real prognosis**

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# Is a diagnosis always a good thing?

- The concept of 'overdiagnosis'

# Overdiagnosis

- Pre-diabetes

# Overdiagnosis

- Pre-diabetes
- Prostate cancer

# Psychiatric (and psychosomatic) diagnoses

- The lack of empirical testing
- Signs and symptoms – a clinical diagnosis
- Descriptions, not explanations

# Overmedicalisation (aka pathologizing)

- Pathologizing normal
- Concept creep
- 'Mental health problems' beginning to label difficulty and distress as illness

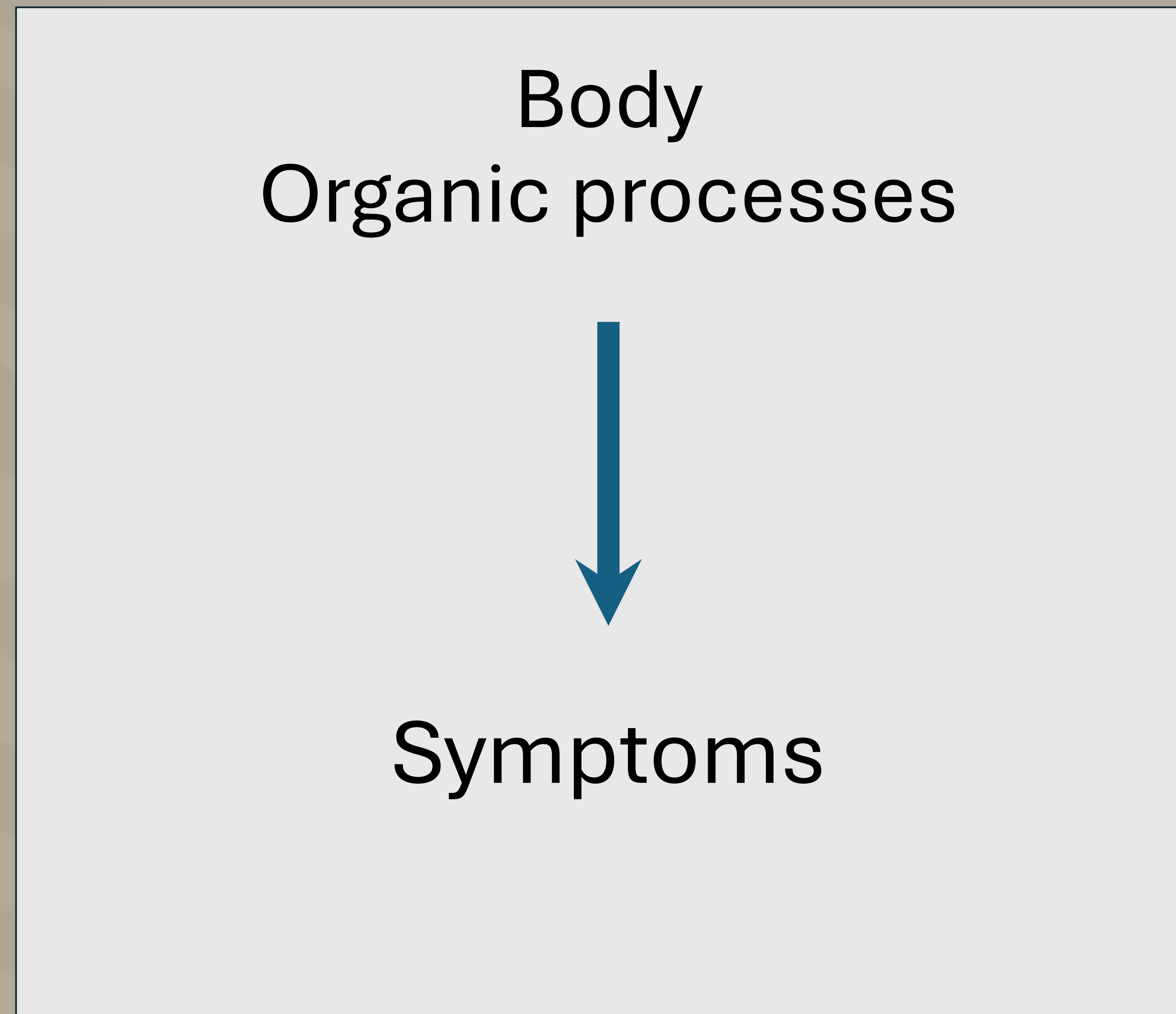
# Biological vs psychological gaze

- Every experience has a biological representation
- Finding a biological change doesn't necessarily identify a cause
- Social / environment issues can often be changed

# Psychosomatic disorders

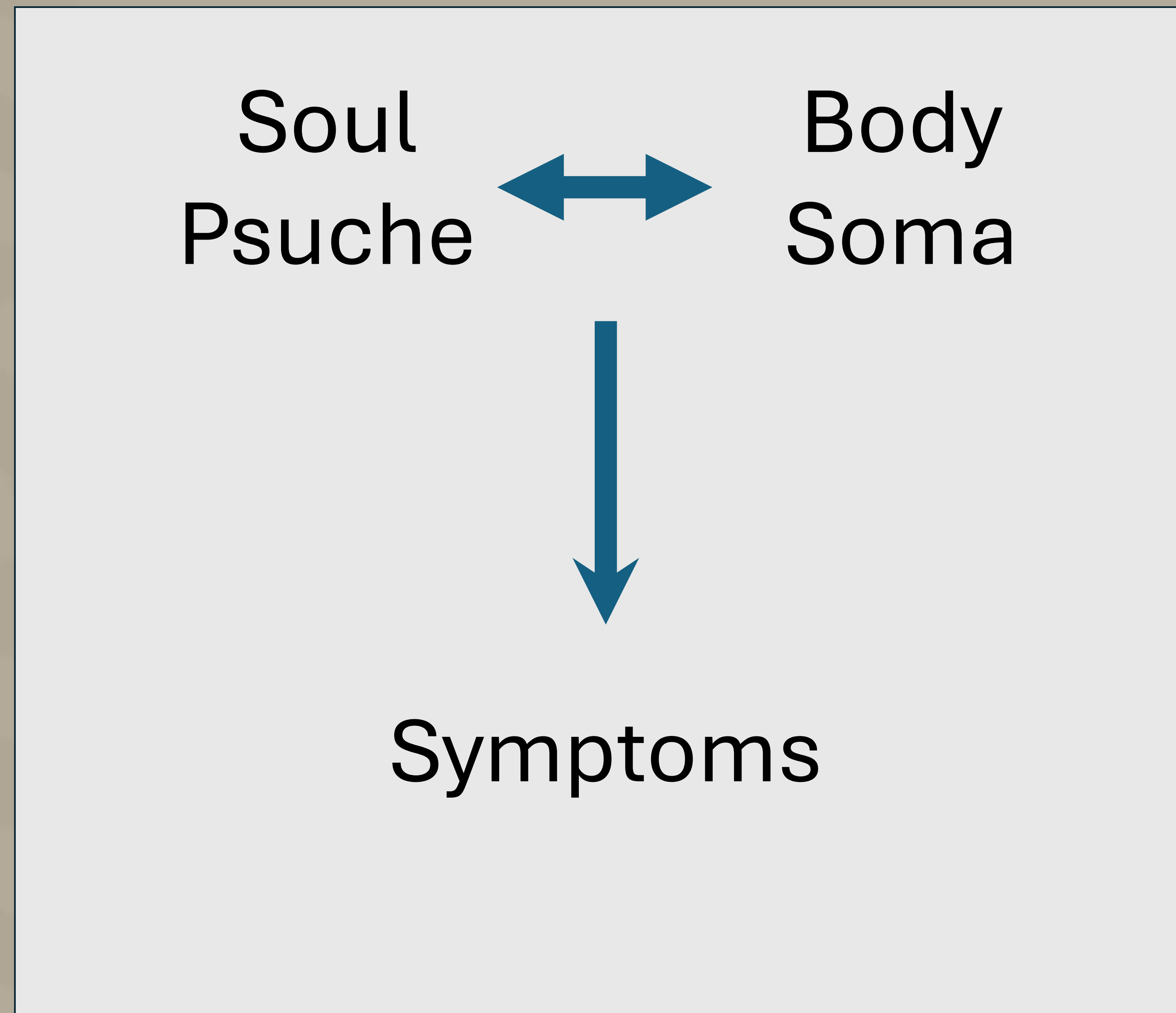
- An unpopular diagnosis
  - *'Are you saying my symptoms aren't real';*
  - *'Do you mean I'm making this up';*
  - *'You think I'm mad'*

# Materialistic View



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# Dualistic View



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# Discuss

- What kind of problems do you think might arise when a diagnosis becomes dominant in a person's life?

# Impact of a diagnosis

- Passivity

# Impact of a diagnosis

- Illness role

# Impact of a diagnosis

- Lowered expectations

# Impact of a diagnosis

- Hyperfocus

# Impact of a diagnosis

- Lowered sense of moral responsibility
- Limit my sense of usefulness to God –

# Impact of a diagnosis

- Constraining potential sources of help

# Two life examples

For a final discussion

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# Malcolm

**Malcolm** is a Christian believer. In his fifties he was diagnosed with autism. He got himself tested at the suggestion of his son, who had himself recently been diagnosed with autism. Malcolm had struggled throughout his career in insurance

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# Malcolm

– there were frequent job changes which were usually precipitated by clashes with a colleague or a client. This diagnosis of autism made sense of his struggles – he had always found noisy and busy environments difficult and working in a team was just hard for him. He now saw that these were all autism related.

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# Malcolm

Malcolm does not like the deficit-based approach to autism and he objects to it being called a disorder. He prefers to identify the things that make an autistic person special. Rather than mask (that is, try hard to appear neurotypical) Malcolm believes autistic people should be their authentic autistic selves.

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# Malcolm

He has become an advocate for autism in your church and champions for a whole range of changes to church services and events. 'Autistic people don't want to be fixed,' Malcolm says. 'Neurotypicals love to think autistic people are the problem but making us fit into your world is our real problem.'

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# Naomi

**Naomi** is a Christian believer. She has experienced ill health for over 20 years and gave up her administrative job more than a decade ago. She has moved back to her parent's home where she and her mother live off state benefits. Her symptoms began with a flu-like illness from which she never seemed to recover.

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# Naomi

Once the acute symptoms passed, she developed new symptoms including weakness of her muscles, a tingling sensation in different parts of her body and palpitations. She also developed brain fog which made it very difficult to read or focus on tasks. Sleep brought no relief – she woke just as weak and tired as before she went to bed.

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# Naomi

Despite a battery of tests, no firm diagnosis emerged. At one stage a doctor diagnosed Naomi with Lyme Disease and treated her with antibiotics. They helped at first, but then the antibody test came back negative and other doctors said it couldn't be the problem.

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# Naomi

Two years ago Naomi and her mother began reading about a condition called Myalgic Encephalomyelitis (ME) on the internet. The descriptions were a perfect match for Naomi's symptoms and they felt sure this must be the diagnosis.

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# Naomi

An online ME patient support group has provided wonderful support and is helping them set realistic expectations. Naomi has done extensive research into treatments for ME, but often struggles to find doctors willing to prescribe for her.

# Discussion #1

- Suppose following a reshuffle of church small groups, Malcolm or Naomi became a member of the group you led. From past contact, you knew the rough outline above.
- How will you approach this meeting?
- Is there anything about your own heart you might need to consider?

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# Discussion #2

- Now suppose you had agreed to meet up with them regularly to try and help them think through this situation biblically, how will you go about this?

# Some ministry principles

1. Don't be scared off!

# Some ministry principles

2. Show patience and compassion

# Some ministry principles

3. Begin with the good

# Some ministry principles

4. Know them (and know how to pray)

# Some ministry principles

5. Neither deconstruct nor join their campaign

# Some ministry principles

6. Treat the sovereignty of God gently

# Some ministry principles

7. See the glory found in our struggles

# Some ministry principles

## 8. Rest on our eternal destiny in Christ

*'What no eye has seen,  
what no ear has heard,  
and what no human mind has conceived' –  
the things God has prepared for those who love him –  
these are the things God has revealed to us by his Spirit.  
(1 Cor 2:9-10)*

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# Final questions and observations

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