

## Resources for clinicians

MSK serious pathology guide - <https://pcrmm.org.uk/wp-content/uploads/2021/04/Serious-Pathology-Guide-FINAL.pdf>

<https://www.retrainpain.org/professional-course> online pain learning (all members of MDT) USD500

<https://www.betterpainmanagement.com/> online pain learning (more medical) AUD315

[www1.racgp.org.au/getattachment/2d7e5c42-334e-4c55-b4c5-c5da504edd4d/Clinical-assessment-and-management-of-vaginismus.aspx](http://www1.racgp.org.au/getattachment/2d7e5c42-334e-4c55-b4c5-c5da504edd4d/Clinical-assessment-and-management-of-vaginismus.aspx)

## For patients

### Understanding pain:

[www.retrainpain.org/](http://www.retrainpain.org/)

<https://painconcern.org.uk/>

[www.aci.health.nsw.gov.au/chronic-pain](http://www.aci.health.nsw.gov.au/chronic-pain)

Understanding Pain in less than 5 minutes, and what to do about it!

[www.youtube.com/watch?v=C\\_3phB93rvI](http://www.youtube.com/watch?v=C_3phB93rvI)

[www.tamethebeast.org/](http://www.tamethebeast.org/)

[www.painscience.com](http://www.painscience.com)

<https://painhealth.csse.uwa.edu.au/>

[www.flippinpain.co.uk](http://www.flippinpain.co.uk)

<https://www.painrevolution.org/>

<https://livewellwithpain.co.uk/>

<https://www.paintrainer.org/login-to-paintrainer/>

<https://www.torbayandsouthdevon.nhs.uk/services/pain-service/reconnect2life/>

<https://www.uhcw.nhs.uk/self-care/persistent-pain/>

Pelvic pain

[www.pelvicpain.co.nz](http://www.pelvicpain.co.nz)

[www.pelvicpaineducation.com](http://www.pelvicpaineducation.com)

[www.bcwomens.ca/our-services/gynecology/pelvic-pain-endometriosis](http://www.bcwomens.ca/our-services/gynecology/pelvic-pain-endometriosis)

[www.whria.com.au](http://www.whria.com.au)

[www.pelvicpain.org.au](http://www.pelvicpain.org.au)

### **Apps**

Curable - <https://www.curablehealth.com/>

Pelvic care for body and mind - [www.ellahealth.co/](http://www.ellahealth.co/)

### **Sleeping well:**

<https://www.justathought.co.nz/insomnia>

<https://thiswayup.org.au/programs/insomnia-program/>

[www.healthnavigator.org.nz/apps/c/cbt-i-coach-app/](http://www.healthnavigator.org.nz/apps/c/cbt-i-coach-app/)

<https://painhealth.csse.uwa.edu.au/pain-module/sleep-and-pain/>

[www.aci.health.nsw.gov.au/chronic-pain/for-everyone/pain-and-sleep](http://www.aci.health.nsw.gov.au/chronic-pain/for-everyone/pain-and-sleep)

### **Flare ups/set backs**

[http://www.srft.nhs.uk/EasysiteWeb/getresource.axd?AssetID=76487&type=full&servicetype=Inline&filename=/Flare\\_up\\_planning\\_Apr\\_19.pdf](http://www.srft.nhs.uk/EasysiteWeb/getresource.axd?AssetID=76487&type=full&servicetype=Inline&filename=/Flare_up_planning_Apr_19.pdf)

[https://www.aci.health.nsw.gov.au/\\_\\_data/assets/pdf\\_file/0008/389015/Flare-Up-Plan-PMN.pdf](https://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0008/389015/Flare-Up-Plan-PMN.pdf)

[https://www.aci.health.nsw.gov.au/\\_\\_data/assets/pdf\\_file/0007/389014/Flare-up-plan-APMA.pdf](https://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0007/389014/Flare-up-plan-APMA.pdf)

[https://my.dchs.nhs.uk/Portals/0/Health%20Psychology%20Coping%20With%20Pain%20at%20its%20Worst\\_1.pdf](https://my.dchs.nhs.uk/Portals/0/Health%20Psychology%20Coping%20With%20Pain%20at%20its%20Worst_1.pdf)

### **Full free Ebooks**

[www.nzps.org.nz/assets/2ee400518f/2204-Pain-Management-Resource-A5-FINAL-online.pdf](http://www.nzps.org.nz/assets/2ee400518f/2204-Pain-Management-Resource-A5-FINAL-online.pdf) - From NZPS

[http://outpatients.tas.gov.au/\\_\\_data/assets/pdf\\_file/0003/172578/CSS\\_-\\_Physiotherapy\\_-\\_Understanding\\_Persistent\\_Pain\\_Booklet.pdf](http://outpatients.tas.gov.au/__data/assets/pdf_file/0003/172578/CSS_-_Physiotherapy_-_Understanding_Persistent_Pain_Booklet.pdf)

[www.greglehman.ca/pain-science-workbooks/](http://www.greglehman.ca/pain-science-workbooks/)

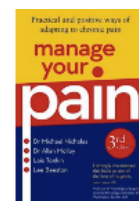
<https://southernrehab.co.nz/wp-content/uploads/2018/08/recoverystrategiesfinalbookjune20171.pdf>

### **Online courses**

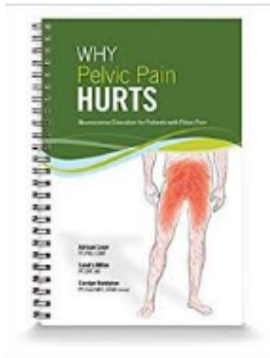
<https://thiswayup.org.au> Many online courses available for mental health and pain. Some are free, others A\$60 or need a 'referral code' from a doctor who will supervise your progress.

### **Books**

Manage your pain, M Nicholas eBook and paperback also in all Christchurch city libraries.



available. About \$20. It is



“Why Pelvic Pain Hurts: Neuroscience Education for Patients with Pelvic Pain teaches you the truth about your chronic pelvic pain; what it is, how the brain and nervous system collaborate to create pain and how you can finally find relief. Written by physical therapists Adriaan Louw, Sandra Hilton and Carolyn Vandyken” (about \$20 from online book stores)



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<sup>2</sup> British Pain Society (patient author)

<sup>3</sup> Physiotherapy Pain Association

<sup>4</sup> Get-Involved—Evolving Through Patient Experience Committee at Torbay Hospital Pain Service

<sup>5</sup> Live Well With Pain

<sup>6</sup> Oxford University Hospitals NHS Foundation Trust, Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences

<sup>7</sup> Division of Rheumatology, Mayo Clinic Florida

<sup>8</sup> FMRI Pain Analgesia/Anaesthesia Imaging Neuroscience group

<sup>9</sup> Oxford City Practice

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## PRACTICE POINTER

### Chronic pain: supported self-management

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#### What you need to know

- Supported self-management is an approach to chronic pain that involves shared decision making, co-production of treatment, and equipping patients with the skills to manage their pain outside of clinical consultations
- Supported self-management is not an all-or-nothing approach but can be tailored to the individual patient
- Longer consultation times may be required initially, but successful supported self-management may reduce consultation rates over time

Chronic pain is a common and disabling condition.<sup>1-3</sup> Increasingly, shared decision making and psychological and behavioural self-management are being prioritised in caring for people with chronic pain, with a diminishing number of pharmacological treatments being supported by guidelines.<sup>4-7</sup> Following a previous article on identifying and diagnosing chronic primary pain,<sup>8</sup> this article aims to help clinicians understand what supported self-management involves and shares practical tips on how to work with patients using this approach, considering what the barriers and facilitators to supported self-management might be.

#### What is supported self-management?

Although no “gold standard” definition of self-management exists in the context of chronic illness, it may be understood as “an individual’s ability to monitor their health condition and effect the behavioural, cognitive, and emotional responses required to support a satisfactory quality of life.”<sup>9</sup> Self-management can also be thought of as “a single approach or combination of approaches that can be initially taught by any health professional or learned by an individual to enable patients to minimise the impact their chronic pain can have on everyday life.”<sup>10</sup> For example, a patient struggling with chronic pain which has led to a reduction in activities might be empowered by setting goals, an aspect of self-management to identify something specific and achievable that they would like to be able to do. Self-management requires the ability to appraise one’s situation and decide on a course of action to achieve a particular goal.<sup>11</sup> The aim is to empower people with long-term conditions to take control of their own treatment<sup>12</sup>—not for patients to be disconnected, highlighting the active participation of the patient,<sup>13</sup> for example in identifying what their priorities are. Rather than focussing on a patient with a particular condition or symptom that needs to be treated, the idea is for healthcare professionals to work with the person as a whole, equipping them

with the skills to address what matters to them most.<sup>14</sup> This involves the patient learning to manage three main aspects of living with chronic pain: medical management (eg, managing medication appropriately and building partnerships with healthcare providers), role management (ie, maintaining, changing, and creating new meaningful behaviours or life roles, eg, changing how to participate in sport), and emotional management (ie, dealing with the emotional sequelae of having a chronic condition such as fear, frustration, anger, and depression).<sup>13</sup> Box 1 summarises the core skills underpinning effective self-management.<sup>13</sup>

#### Box 1: Summary of skills involved in supported self-management<sup>13</sup>

- Problem solving—defining the problem, generating possible solutions, implementing solutions, and evaluating results.
- Decision making—this can be part of problem solving but is also part of ongoing day-to-day decisions in response to changes in disease condition, eg, What should I do if a new exercise programme triggers worsening pain?
- Resource utilisation—how to find and use a range of resources.
- Building a partnership between patient and healthcare provider—being able to report the trends of the condition, make informed choices about treatment, and discuss them with the healthcare provider.
- Taking action—learning how to change behaviour; making a short term action plan is one of the most important skills involved.

While self-management calls for the patient to adopt an active role, supported self-management acknowledges the equally important role of the clinician. In supported self-management, patients and clinicians share decision making and treatment as a co-production.<sup>14,15</sup> For people living with persistent illness, empathetic listening, forming a connection between the patient and the healthcare professional can be therapeutic.<sup>15,16</sup> Key features of supporting self-management include: validating the experience of chronic pain,<sup>17</sup> seeing the patient as a complete person in the context of their whole life,<sup>14,15</sup> and recognising the widespread impact of chronic pain to facilitate appropriate referral to self-management interventions (SMIs), consistent with the patient’s current capacity and values.<sup>14</sup>

No universally accepted definition exists for SMIs, although they are generally understood to be interventions designed to improve participants’

health status or quality of life by enhancing their self-efficacy and increasing their ability to manage their own health through the development of core skills.<sup>18,19</sup> Given the multidimensional nature of self-management,<sup>9,13</sup> a wide variety of SMIs is currently available.<sup>9</sup> SMIs typically include more than one of the following components: psychological therapies, mind-body therapies, physical activity, lifestyle adaptations, and medical education.<sup>18,19</sup> Table 1 summarises

three types of intervention commonly offered to people living with chronic pain, and the associated topics that may be covered in each.<sup>11</sup> SMIs can be delivered through group sessions, individual sessions, telephone calls, online meetings and websites, smartphone apps, self-study toolkits, and/or any combination of the above, and can be supported and delivered by a variety of healthcare professionals.<sup>11,18,20-23</sup>

Table 1 | Common self-management interventions<sup>12</sup>

Intervention	Topics often included
Stanford model	<ul style="list-style-type: none"> <li>Self-management principles/responsibilities</li> <li>Goal setting and action plans</li> <li>Pain management tools (eg. use of medications and multiple cognitive strategies)</li> <li>Problem solving</li> <li>Physical activity and exercise</li> <li>Healthy eating</li> <li>Dealing with difficult emotions and depression</li> <li>Fatigue and sleep</li> <li>Working with your healthcare provider</li> </ul>
Acceptance and commitment therapy	<ul style="list-style-type: none"> <li>Principles of the pain-avoidance-suffering cycle</li> <li>Identifying values/valued activities, and gradually increasing exposure to value-directed behaviour (instead of pain-directed behaviour)</li> <li>Cognitive defusion (identifying and observing negative thoughts without acting on them, and distancing oneself from them)</li> <li>Mindfulness</li> <li>Accepting and being willing to engage with pain</li> <li>Committing to action and identifying obstacles to desired action</li> <li>Planning for future action and obstacles</li> </ul>
Modified cognitive-behavioural therapy	<ul style="list-style-type: none"> <li>Cognitive restructuring (eg. identifying and evaluating catastrophic thinking and constructing realistic alternatives)</li> <li>Identifying and restructuring pain avoidance beliefs and behaviours</li> <li>Behavioural activation (eg. pacing and activity scheduling)</li> <li>Understanding biopsychosocial influences of pain</li> <li>Goal setting</li> <li>Lifestyle changes (eg. exercise)</li> <li>Self-regulatory skills (eg. progressive muscle relaxation and breathing exercises)</li> <li>Pain management skills (eg. attention diversion and stress-coping skills)</li> <li>Strategies to prevent relapse</li> </ul>

### What is the evidence for supported self-management interventions?

Some low to moderate quality evidence shows that SMIs for chronic pain may provide some benefit, with no evidence of harm. Structured systematic reviews and meta-analyses of SMIs for chronic pain have suggested, at best, small improvements in physical function, pain intensity, and self-efficacy, but lack of evidence along with heterogeneity of content, delivery, and outcome measures used are repeatedly highlighted as limitations.<sup>18,22,24,25</sup> UK National Institute for Health and Care Excellence (NICE) chronic pain guidance from 2021<sup>26</sup> recommends clinicians to consider both cognitive behavioural therapy (CBT) and acceptance and commitment therapy (ACT) but did not recommend specific pain management programmes.

However, patient organisations point out that most patients with long term conditions (including chronic pain) want to self-manage

more, with support from clinicians.<sup>27</sup> Health profession associations, patient representatives, and NICE agree that patient centred care, which supports self-management, is a patient right and best practice.<sup>27-29</sup> A qualitative systematic review from 2018 in patients with chronic pain suggests beneficial effects in which a supportive, empowering environment alongside a therapeutic alliance between patients with chronic pain and clinicians can foster other positive feelings such as a greater sense of being able to cope.<sup>7</sup>

Several barriers and facilitators to self-management of chronic pain have been identified,<sup>7,10,11,30</sup> as summarised in table 2, and clinicians may be well positioned to identify and help individuals address them.<sup>11</sup> For example, if a person is experiencing lack of support from family and friends, a clinician can help them explore other sources of support, such as social support from other individuals with the same condition or attending a support group.

**Table 2 | Common barriers and facilitators of self-management**

	Barriers	Facilitators
External influencing factors	Lack of support from clinicians, family, friends, and the community	Supportive environment—many patients feel isolated and the option of joining a group with similar conditions can help improve participation and sense of belonging
	Communication problems can include conflicting advice, dismissive comments about pain, and non-individualised self-management advice	Accessibility—easy access to healthcare services in terms of location, availability, and affordability help to improve attendance alongside programmes tailored to specific conditions
Internal influencing factors	Sustained motivation—dedicating time on a day-to-day basis alongside engaging with psychological techniques requires a lot of energy	Feeling empowered—accepting pain and acknowledging that it is possible to live life despite pain. Taking an active role in self-management can be facilitated through increased understanding of chronic pain
	Physical factors such as flares of pain and functional limitations can lead to fear avoidance and are a barrier to exercise in particular.	Knowledge—increased patient understanding improves recognition of self-management benefits in the long term, supported by goal setting strategies.
	Psychological factors such as distress from ongoing pain, stress, fatigue, anxiety, and depression alongside remaining in search for a biomedical explanation for the pain are barriers to engaging with self-management strategies	Self-discovery—being able to distinguish self from pain

## How can clinicians facilitate supported self-management?

A therapeutic relationship based on trust and recognition of the patient as an individual must first be established for a clinician to provide support.<sup>15</sup> Helping patients understand more about their pain can be empowering.<sup>6, 11</sup> Inviting them to engage in shared decision making may help individuals see that they themselves have the power to achieve improvement, rather than a clinician.<sup>11</sup> An understanding of the value and role of self-management allows this approach to be seen as a valid therapeutic modality alongside other treatments, such as medication. **Box 2** contains resources which may be helpful to patients and clinicians at this stage. Many patients with chronic pain benefit from longer appointment times and continuity of care.<sup>31</sup> Continuity of care saves time and resources in the long term because the foundation of trust, treatment history, and patient values are familiar.<sup>32</sup> As an individual increases their self-management capacity, they will likely require less frequent and shorter appointments.<sup>14</sup>

### Box 2: Resources for clinicians and patients

#### Pain education

- Pain and the brain, Footsteps Festival 2021. <https://my.livewellwithpain.co.uk/festival-category/pain-and-the-brain/>
- RetrainPain. <https://www.retrainpain.org/>
- Flippin' pain. <https://www.flippinpain.co.uk/understanding-pain/>

#### Free online self-management programmes

- Live Well with Pain. A not-for-profit 10 step programme developed by multidisciplinary clinicians. <https://livewellwithpain.co.uk/>
- PainTrainer is an interactive pain management course comprising eight sessions, developed by an international HCP team from University of Melbourne, Australia, Duke University Medical Center, and Hackensack University Medical Center, USA. <https://www.paintrainer.org/login-to-paintrainer/>
- ReConnect2Life. An interactive programme from NHS Torbay and South Devon Foundation Trust with six modules: pain neuroscience education, medication, movement, sleep, emotions and cognition, and goal setting. <https://www.torbayandsouthdevon.nhs.uk/services/pain-service/reconnect2life/>
- Pain Concern. A charity with a confidential free helpline, community patient support groups and a free self-management navigator tool. <https://painconcern.org.uk/product/self-management-navigator-tool/>

- The pain toolkit. Developed by Pete Moore, an expert patient, with free tools and at-cost books and workshops. Its Pain Tools page provides a free 12 step programme. <https://www.paintoolkit.org/pain-tools>

#### Resources for living with pain

- NHS. <https://www.nhs.uk/live-well/healthy-body/10-ways-to-ease-pain/>
- International Association for the Study of Pain. <https://www.iasp-pain.org/Education/Content.aspx?ItemNumber=1723&navItemNumber=678>

#### Resources for managing comorbidities of chronic pain

- NHS 10 tips on beating insomnia and sleep hygiene.
  - <https://www.nhs.uk/live-well/sleep-and-tiredness/how-to-get-to-sleep/>
  - <https://www.nhs.uk/every-mind-matters/mental-health-issues/sleep/>
- NHS Fitness Studio. <https://www.nhs.uk/conditions/nhs-fitness-studio/>
- The Chartered Society of Physiotherapists. Online video physiotherapy exercises separated by condition: <https://www.csp.org.uk/conditions>
- Oxford Mindfulness Centre. Free audio sessions: <https://www.oxfordmindfulness.org/learn-mindfulness/resources/>
- Moving Medicine. A Faculty of Sport and Exercise Medicine initiative with consultation guides to help clinicians broach the conversation on activity: <https://movingmedicine.ac.uk/>

#### Charities

- Pain Concern, Action on Pain, Versus Arthritis, BackCare

#### Apps

- Sleepio, Calm, Headspace

Much can be learnt from listening to patients who live with chronic pain (**box 3**). Patients emphasise the importance of personalised care and the dynamic, non-linear nature of self-management. Rather than an all-or-nothing approach, supported self-management allows patients to choose from a variety of interventions, consistent with their health status, capacity, and values. Clinicians play an important role in supporting patients during all parts of the self-management journey.

### Box 3: What can patients teach us about living with chronic pain?

#### Supported self-management is a dynamic process

"Self-management of chronic pain is a constant learning process. It's a strategy that develops over time and is tweaked and adapted as and when needed. It's not something that you can learn once, check off, and immediately excel at."

#### Improvement takes time

"Progress is rarely linear. Inevitably, there are some setbacks along the way."

#### Acknowledge the impact of chronic pain on quality of life

"Living with chronic pain has forced me to reassess my values and to reconsider what is most important to me. This process of realigning myself with my values has given me a much greater sense of purpose and gratitude."

#### Take an individual approach

"We are all unique and nobody wants to be in pain."

#### Language matters

"Exercise conjures up visions of Lycra clad joggers running down the street or pumping iron in the gym. Movement or activity sounds much less intimidating and far more achievable. Whenever clinicians start talking to chronic pain patients about 'exercise,' we all just switch off right there. Talk to us about what movement and activity we enjoy, eg, dancing, walking, swimming—all gentle of course—and the conversation will go much further."

Quotes are from members of the British Pain Society Patient Voice group

Clinicians can also direct patients to high quality resources relating to a broad range of management options, enabling the patient to access the information that they need to make informed decisions regarding treatment options as recommended by NICE (box 4).<sup>11</sup>

### Box 4: Summary of management options for chronic primary pain (according to NICE)<sup>5</sup>

#### Exercise programmes and physical activity

- Offer a supervised group exercise programme
- Encourage people with chronic primary pain to remain physically active for longer term general health benefits

#### Psychological therapy

- Consider acceptance and commitment therapy or cognitive behavioural therapy

#### Acupuncture

- Consider a single course of acupuncture or dry needling, within a traditional Chinese or western acupuncture system

#### Pharmacological management

- Consider an antidepressant after a full discussion of the benefits and harms

Individual clinicians may not feel confident to support self-management or feel that they lack the necessary skills. However, resources are also available to support clinicians to develop these skills<sup>33</sup> and many specialist services now offer chronic pain self-management referral options alongside more traditional chronic pain clinics.

### What other sources of self-management support are available?

The negative impacts of living with chronic pain may ultimately include social isolation, loss of employment, and the inability to engage in previous interests and activities, with obvious implications for mental and physical health.<sup>17</sup> For example, a UK Biobank cross-sectional study of more than 500 000 participants found that

loneliness and social exclusion are linked to higher chronic pain prevalence.<sup>34</sup>

Peers living with the same or similar condition are thus an important source of support,<sup>11 13 35</sup> as they can provide unique strategies and practical examples of self-management. For example, peers are able to exchange ideas on managing symptoms, validate experience of pain using their own experience, and serve as realistic, motivational role models for having improved quality of life while living with pain.<sup>35</sup>

Alongside shared decision making, multisectoral and multidisciplinary support can be helpful to facilitate self-management, for example utilising third sector provision or referral to a health coach or social prescriber. Community based organisations such as Live Well with Pain support and offer personalised courses for patients in chronic pain self-management.

Social prescribing—sometimes referred to as community referral—is another approach that may help meet the holistic needs of an individual, facilitating referral to a range of local, non-clinical services.<sup>36</sup> Different models of social prescribing exist, but in the UK most involve a link worker, who is able to spend time with the person, identify social issues that may be affecting their health and wellbeing, and support the person to take control of their health and wellbeing.<sup>36</sup> Although it remains unclear how effective social prescribing is,<sup>37</sup> preliminary data from the experiences of people living with chronic pain suggest that social support may reduce pain and support people to cope with chronic pain.<sup>38</sup> In the UK, most GP practices are able to refer to a social prescriber or link worker.

### Education into practice

- How often do you discuss the option of self-management with patients living with chronic pain?
- When might you consider referring a person living with chronic pain to a social prescriber?

### How patients were involved in the creation of this article

Louise Trewern, chronic pain patient advocate, is a co-author of this article and has provided key input from a patient perspective. Through her role, expert patient representatives from the Patient Voice and the Footsteps Festival Expert Patient Team provided feedback on the article content, highlighting in particular the importance of language in the consultation and the role of education early on.

### How this article was created

A literature search was conducted across Ovid Medline, PubMed, Cochrane Collaboration, and NICE for chronic pain clinical guidelines and systematic reviews. The most recent guidelines and systematic reviews were selected to draft the initial outline, and we collated the most recent evidence. Finally, the clinical experience of senior authors was added alongside patient perspectives.

Contributorship and the guarantor: YK, JL, LT, DM, and AS conceived the article and are guarantors. All authors wrote and reviewed the article, created the boxes, and helped advised on the figures. LT was the contact for patient involvement.

Competing interests: The BMJ has judged that there are no disqualifying financial ties to commercial companies. The authors declare the following other interests: none.

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# Chronic pelvic pain with normal laparoscopic findings

CPD 

Susan F Evans

## Background

An expectation that pelvic pain should be 'visible' at laparoscopy can lead to disappointment for patients and confusion among health practitioners when no abnormalities are found.

## Objective

This article outlines an approach for understanding, explaining and managing chronic pelvic pain in women with a normal laparoscopy. It divides symptoms into those associated with pelvic organs, pelvic muscles, the central nervous system and psychosocial factors.

## Discussion

Management requires considering the origin of the pain, the extent of pelvic muscle reaction to the pain, the severity of central pain sensitisation and additional psychosocial aggravating factors. Considering symptoms within these categories provides a useful framework to best target therapeutic interventions. A patient who knows that management of her pain will continue and that an absence of lesions does not diminish the validity of her pain experience can feel confident in herself and her health practitioner.

**WITH THE WELCOME** enhanced awareness of endometriosis in our community has come the expectation that all pain can be 'seen' at laparoscopy. There is the anticipation that a laparoscopy will find and remove endometriosis lesions and patients' pain symptoms will be cured. Any self-doubt or disbelief from family, friends or health practitioners will be shown as misplaced. Their suffering will be validated, and support will be forthcoming. Unsurprisingly, where the expectation that 'real' pain will be visible has been perpetuated, your patient might be sorely disappointed and embarrassed when their laparoscopy shows a normal, healthy and likely fertile pelvis. Anxiety and embarrassment are frequent emotions when in fact a normal pelvis is always the best outcome.

This requirement that female pelvic pain should be visible is a high and unfair 'proof of pain' bar that is not applied to most other pain conditions. For example, it is generally accepted that a migraine is painful, yet we do not require migraine sufferers to have visible brain lesions to verify that their pains are real.

The visual confirmation of a healthy-looking pelvis can be celebrated by a patient where she understands that not all pain can be seen at surgery and that her practitioner will continue to work with her to manage her pain. Support will continue, and she is no less deserving of care than women with endometriosis present.

So, where to now? What's happening? Why does she have pain?

To explain this, the concepts around chronic pelvic pain require reframing.

This article outlines a practical general practice-based approach to the care of patients assigned female at birth: girls, women and non-binary and trans individuals.

## An approach to management of pelvic pain syndrome

This article describes a symptom-based approach suited to general practice that considers pelvic pain as, first, a pain syndrome with multiple symptoms and, second, a condition where endometriosis is commonly found but need not be present. In this context, there need be no distress where a laparoscopy shows no lesions. The absence of findings means that she is now less likely to require further surgery. The non-surgical management of her pain and pain-related symptoms that is required for all types of chronic pelvic pain continues.

Pelvic pain syndrome includes a wide range of symptoms both within and outside the pelvis that cluster together. Figure 1 describes the typical symptoms occurring with dysmenorrhoea.<sup>1</sup> Like all syndromes, none of the symptoms are essential for a diagnosis, but they are all more common among this group than the general community. These symptoms



can be divided into four categories: pain from pelvic organs with or without endometriosis; pain from pelvic muscles; pain generated in the central nervous system (CNS); and additional psychosocial factors, including early adverse life events and psychosocial stress. Endometriosis, if present, adds another significant layer of complexity to pain and fertility management but is not essential. Where this approach has been explained before laparoscopy, there is no need for patient distress following negative findings. This approach involves gynaecologists and allied health practitioners where their skill sets are required but is predominantly a general practitioner-centric model. It provides a matrix for symptom management and reduces stress on both sides of the consultation desk. Taking a history is facilitated by use of the pelvic pain questionnaire available through the Pelvic Pain Foundation of Australia ([www.pelvicpain.org.au](http://www.pelvicpain.org.au)).

#### Pain from pelvic organs with or without endometriosis

A common life scenario involves a girl who was generally well until puberty.

Dysmenorrhoea begins at or soon after menarche, and initially she is well between periods.<sup>2</sup> After a variable amount of time,<sup>2</sup> pain becomes more complex in a proportion of patients with dysmenorrhoea. Additional pelvic organs become symptomatic and join the uterus as *pain drivers* of her individual manifestation of pelvic pain syndrome (Figure 2). The shared dermatomes, adjacent ascending spinothalamic tracts and pelvic muscle associations mean that sensations originating in any one of these organs might feel similar (Figure 3), making it difficult for women to differentiate the cause of pain during pain flares.<sup>3</sup>

#### Useful questions

- Did you have bladder or bowel problems when you were a child before your periods started?
- What were your periods like as a teenager?
- Do you have any bowel or bladder problems now?

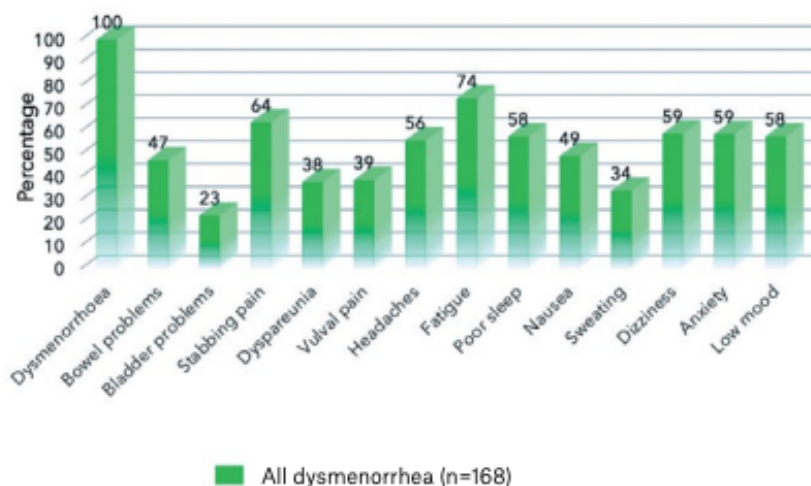
These questions help determine which of the pelvic organs have been involved in initiating and driving the overall chronic pelvic pain picture.

#### Management plan

This approach aims to reduce stimuli from each symptomatic organ in the pelvis. Dysmenorrhoea provides a stimulus to persistent pelvic pain with every menstrual period, and prolonged vaginal bleeding will provide a prolonged stimulus.

Where dysmenorrhoea has been a major pain driver, of both pelvic muscle pain and central pain sensitisation, then menstrual suppression will both avoid uterine pain and reduce the stimulus to pelvic muscle spasm (often described as the *worst pains*) and the CNS (where many of the *feel bad* symptoms are generated). While this has commonly been achieved with the oral contraceptive pill, a continuous progestogen such as norethisterone 5 mg or dienogest 2 mg might be more effective at reducing symptoms. A levonorgestrel-releasing intrauterine device is best inserted after hormonal suppression

**Percentage of women with dysmenorrhea who report additional symptoms**



**Figure 1.** The range of symptoms that cluster with dysmenorrhoea in women with pelvic pain. Reproduced with permission from Evans et al.<sup>1</sup>



**Figure 2.** The pelvic organs, with or without endometriosis, commonly involved in chronic pelvic pain.

Reproduced with permission from Dr Susan F Evans P/L.

has thinned the endometrium for 2–3 months and after pelvic muscle hypertonus and central pain sensitisation issues have been reduced. A diclofenac suppository (100 mg or 50 mg if sensitive) is useful for flares when bleeding or overnight during periods. Tranexamic acid to reduce menstrual bleeding might also be beneficial.<sup>4</sup>

Over time, it is common for the bowel and sometimes the bladder to also become symptomatic, presenting as constipation, food intolerances or urinary tract infection-like episodes with negative urine culture. The aching, stabbing pelvic muscle pains of pelvic muscle pain might co-exist and worsen when bowel symptoms flare. Your patient has more to gain from a good diet and soft bowel action than other women and more to lose from a poor diet. The management of bowel and bladder pain symptoms is outlined in *Endometriosis and pelvic pain*,<sup>5</sup> and referral to a gastroenterologist or urologist might be required in a small proportion of cases.

### Pain from pelvic muscles

Pain from pelvic muscle hypertonus is frequently overlooked yet often described

as the *worst pain* among a patient's many symptoms (Figure 4). Inflammation in a pelvic organ can induce inflammation in the CNS, causing increased tension in the pelvic muscles. During a flare, a worsening of pelvic muscle hypertonus can result in pelvic muscle spasm with severe pain. Effectively, the patient is having a muscle cramp inside the pelvis during flares. Commonly involved muscles are the muscles of the pelvic floor and lower anterior abdominal wall, the obturator internus bilaterally and the gluteus medius.

### Useful questions

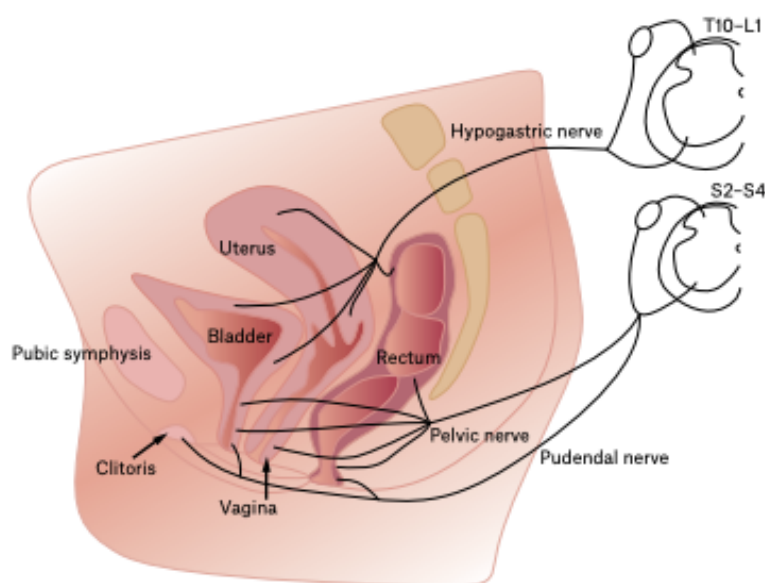
| a. *What does the pain feel like?*

An aching or stabbing pain on one or both sides of the pelvis that is affected by position or movement, better with a heat pack or hot bath, makes it difficult to walk and feels best when curled up in a ball usually reflects pain in the obturator internus, the strong muscle on the sides of the pelvis that controls the hip joint. An ultrasound probe will cause pain when it presses laterally,

and pain often radiates to the back, to the hip or down the front of the leg. One finger vaginal examination palpating laterally to the obturator internus, with the patient's knee pressed out against the practitioner's outside hand, will find the tender muscle and confirm the diagnosis.<sup>6</sup> Stabbing pain up the rectum or vagina with pain during intercourse, with tampons or with defecation often represents high muscle tone in the pelvic floor muscles. There might be incomplete bladder emptying due to pelvic floor muscle contraction and pain might persist to the next day after intercourse. Observation of contraction and relaxation of the vaginal introitus will reveal that the muscle is tight and the vaginal introitus is relatively closed.

| b. *When do you get these pains?*

These pelvic muscle pains will worsen whenever one of the pelvic organ pain drivers is active. For example, during a period, she might describe pain from uterine cramps centrally but also stabbing pain from the obturator internus. She might recognise that she experiences similar pain when constipated.



**Figure 3.** The shared sensory innervation of the pelvic organs via the hypogastric nerve to similar spinal segments.

Reproduced with permission from Professor P Jobling.

### Management plan

Education on the role of pelvic muscles in the patient's pain experience is valuable, reassuring and beneficial. The pain is severe, but she need not fear that it is dangerous. Frequently, women reflect that the aching, stabbing pain has been present from early years, often attributed to other causes. She might also reveal that surgical procedures were undertaken for this pain, while the actual cause of pain was not recognised.

Management includes keeping moving, specific stretches, pelvic physiotherapy with a physiotherapist who offers muscle down training, review to ensure the patient's current activities are not aggravators, pelvic muscle relaxation and management of the particular pelvic organ driving the pelvic muscle pain. A walk each day and a focus on movement and muscle relaxation rather than strenuous exercise and muscle tightening is a great start. While a laparoscopy involves muscle relaxant as part of the procedure, which might contribute to short-term relief of pelvic muscle spasm, pelvic muscle hypertonus recurs where not specifically treated

Botulinum toxin injections provide 3–6 months of relief, where available.<sup>7</sup> However, these injections are most effective when other aspects of the pain, including the initial pain driver and the pain sensitisation, have been fully managed. Further information on stretches and a pelvic muscle relaxation audio download are available at [www.pelvicpain.org.au](http://www.pelvicpain.org.au).

### Pain generated in the central nervous system

The presence of persistent pain has been extensively linked to inflammation and neuroglial changes in the CNS (Figure 5).<sup>8,9</sup> Asking your patient to complete a pain body map such as the map included on the Pelvic Pain Foundation of Australia questionnaire ([www.pelvicpain.org.au](http://www.pelvicpain.org.au)) will allow you to better understand the relative balance between these two factors. Where pain is purely pelvic, managing pelvic issues alone might be sufficient. This might

be the situation in the early years where dysmenorrhoea alone is her concern. Where pain is widespread, there are multiple autonomic symptoms and pain is present on most days, managing pelvic issues only is rarely sufficient. Surgical treatments, including hysterectomy, are much less likely to resolve pain in this situation.<sup>10</sup> CNS-generated pain sensitivity is a major part of her pain and requires management. This might be the situation in women with pain on most days, fibromyalgia-like symptoms, fatigue, anxiety, low mood, poor sleep, nausea, dizziness, fainting, headaches or poor cognition.

### Useful questions

a. How many days per month do you have pain or discomfort?

b. Do you have fatigue, poor sleep, nausea, anxiety, low mood, dizziness, brain fog, headaches or difficulty concentrating?

Where pain is present on most days or these additional symptoms are present, a relatively larger central than peripheral component of the patient's pain is present.

Management involves pain education that explains the wide range of systems involved and that surgical options, including hysterectomy, might be less effective strategies. Useful strategies include maintaining purposeful activity in life, physical activity, pain psychology and pain medications. Amitriptyline in low dose (5–25 mg early evening) is the most effective of the medications,<sup>11</sup> particularly as it also reduces headache and improves sleep. Duloxetine at 30–60 mg in the morning is particularly effective with higher levels of central pain sensitivity and where anxiety or low mood are present. Gabapentin and pregabalin have low effectiveness in most cases of dysmenorrhoea-related pain.<sup>12</sup> A pain psychologist might be invaluable. The purpose of the consultation is to address how psychological factors affect their approach to chronic pain. The combination of pelvic organ and CNS pain is called *nociplastic pain* and multi-symptom pain conditions are sometimes referred to as *chronic overlapping pain syndromes*.

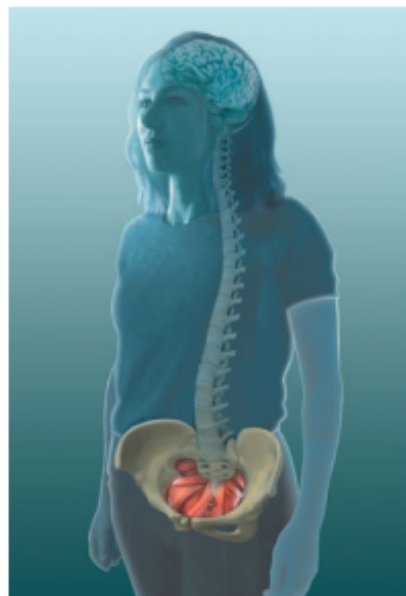
Importantly, CNS-generated pain can be induced or worsened by regular use of opioids. It is imperative that the first practitioner to prescribe regular opioids understands the heavy burden of responsibility that they take on when writing the first prescription for regular opioid use. There is increasing evidence that the changes in the spinal cord induced by regular opioids are not fully reversible.

### Aggravating factors

Early adverse life events, psychosocial stress, sleep deprivation, physical inactivity and a lack of life purpose will all contribute to the severity and life impacts of pain.

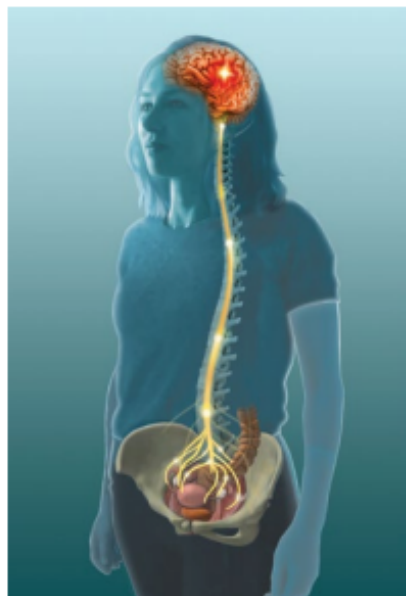
### Conclusion

From a health practitioner's perspective, caring for patients with so many symptoms, especially where there is co-existent societal, educational and financial disadvantage, can be daunting. None of us leave our training programs with all the skills required to manage all these symptoms. However,



**Figure 4.** The pelvic muscles commonly found to be hypertonic in patients with pelvic pain: puborectalis and obturator internus.

Reproduced with permission from Dr Susan F Evans P/L.



**Figure 5.** Enhanced activation of the central nervous system present in patients with pelvic pain.

Reproduced with permission from Dr Susan F Evans P/L.

with a little upskilling and support, becoming an effective practitioner for women with pelvic pain is enormously satisfying.

This article has provided a framework for the assessment and management of pelvic pain where laparoscopic findings are normal. It divides the symptoms into four components: pain from pelvic organs, pain from pelvic muscles, pain generated in the CNS and additional psychosocial adverse life events.

Most of these patients are young with a full life ahead of them, especially where pain education and symptom management are successfully combined.

### Key points

- Patients might feel embarrassed or distressed when laparoscopy findings are normal.
- A diagnosis of pelvic pain syndrome does not require endometriosis to be present.
- Pain from pelvic muscle spasm is a frequent cause of emergency department presentation.
- A CNS component is present in pain present for more than 3–6 months.
- A structured approach to diagnosis and management reduces stress for patients and clinicians.

### Author

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### References

1. Evans SF, Brooks TA, Esterman AJ, Hull ML, Rolan PE. The comorbidities of dysmenorrhea: A clinical survey comparing symptom profile in women with and without endometriosis. *J Pain Res* 2018;11:3181–94. doi: 10.2147/JPR.S179409.
2. Hardi G, Evans S, Craigie M. A possible link between dysmenorrhoea and the development of chronic pelvic pain. *Aust N Z J Obstet Gynaecol* 2014;54(6):593–96. doi: 10.1111/ajo.12274.
3. Jobling P, O'Hara K, Hua S. Female reproductive tract pain: Targets, challenges, and outcomes. *Front Pharmacol* 2014;5:17. doi: 10.3389/fphar.2014.00017.
4. Sachedina A, Abu Bakar M, Dunford AM, Morris A, Nur Azurah AG, Grover SR. Dysmenorrhea in young people: Experiences from a tertiary center with a focus on conservative management. *J Obstet Gynaecol Res* 2021;47(1):352–58. doi: 10.1111/jog.14532.
5. Evans S, Bush D. Endometriosis and pelvic pain. Dr Susan F Evans, 2016. Available at [www.pelvicpain.org.au/wp-content/uploads/2023/03/Endometriosis-and-Pelvic-Pain.pdf](http://www.pelvicpain.org.au/wp-content/uploads/2023/03/Endometriosis-and-Pelvic-Pain.pdf) [Accessed 6 November 2023].
6. Sarton J. Assessment of the pelvic floor muscles in women with sexual pain. *J Sex Med*. 2010;7(11):3526–9. doi: 10.1111/j.1743-6109.2010.02059.x.
7. Mooney SS, Readman E, Hiscock RJ, Francis A, Fraser E, Ellett L. Botulinum toxin A (Botox) injection into muscles of pelvic floor as a treatment for persistent pelvic pain secondary to pelvic floor muscular spasm: A pilot study. *Aust N Z J Obstet Gynaecol* 2021;61(5):777–84. doi: 10.1111/ajo.13396 PMID:34128537.
8. Gosselin RD, Suter MR, Ji RR, Decosterd I. Glial cells and chronic pain. *Neuroscientist* 2010;16(5):519–31. doi: 10.1177/1073858409360822.
9. Dodds KN, Beckett EAH, Evans SF, Grace PM, Watkins LR, Hutchinson MR. Glial contributions to visceral pain: Implications for disease etiology and the female predominance of persistent pain. *Transl Psychiatry* 2016;6(9):e888. doi: 10.1038/tp.2016.168.
10. As-Sanie S, Till SR, Schrepf AD, et al. Incidence and predictors of persistent pelvic pain following hysterectomy in women with chronic pelvic pain. *Am J Obstet Gynecol* 2021;225(5):568.e1–11. doi: 10.1016/j.ajog.2021.08.038.
11. Finnerup NB, Attal N, Haroutounian S, et al. Pharmacotherapy for neuropathic pain in adults: A systematic review and meta-analysis. *Lancet Neurol* 2015;14(2):162–73. doi: 10.1016/S1474-4422(14)70251-0.
12. Horne AW, Vincent K, Hewitt CA, et al; GaPP2 collaborative. Gabapentin for chronic pelvic pain in women (GaPP2): A multicentre, randomised, double-blind, placebo-controlled trial. *Lancet* 2020;396(10255):909–17. doi: 10.1016/S0140-6736(20)31693-7.