

SUPPORTING PEOPLE WITH ARTHRITIS WAITING FOR SURGERY

A six-part package to support people
with arthritis waiting for joint
replacement surgery in England



**ALL OF US
VERSUS
ARTHRITIS**

A resource guide from Versus Arthritis for MSK leads at ICSs, PCNs, musculoskeletal interface services and providers of orthopaedic surgery

THE URGENT NEED FOR SUPPORT

Versus Arthritis launched the Impossible to Ignore campaign to ensure that the needs of people with arthritis were prioritised by policymakers as plans for the COVID-19 recovery were developed.¹

Waiting times for elective surgery were already rising before the pandemic. COVID-19 has accelerated this trend, with record numbers of people with arthritis now waiting longer than ever for joint replacement surgery. For many this means living with symptoms that are impossible to ignore and which have a devastating impact on their quality of life.

As people with arthritis wait to access much needed treatment, it is critical that they are not left behind, struggling in pain. In a recent survey (see headline results on opposite page), people with arthritis waiting for surgery identified a number of interventions which they needed to be able to cope while waiting for their treatment. In this

resource guide, Versus Arthritis has built on these themes to identify a six-part support package which will help to meet the needs of people with arthritis who are on surgery waiting lists.

This guide was written in consultation with people with musculoskeletal conditions waiting for joint replacement surgery. The implementation of this support package could mean better health and wellbeing, and less distress, for people with arthritis waiting for a joint replacement or other types of orthopaedic surgery.

This resource is not intended to be a substitute for joint replacement surgery. It is intended only as a resource to ensure patients receive the holistic care and support they need while waiting. Versus Arthritis' priority is to see current waiting times fall as part of the post-pandemic recovery, so people can receive the transformative joint replacement surgery they need in a timely manner.

Versus Arthritis surveyed people waiting for joint replacement surgery and found that²:



79%

reported their physical health had **worsened**



89%

said their pain levels had **deteriorated**



90%

reported **reduced mobility**



79%

said they were now **less independent**



72%

reported a deterioration in their **mental health**

ADOPT OUR SIX-PART SUPPORT PACKAGE

1

Clear communication

must be provided to people about when they can expect to have their surgery and receive the care and services they need in the meantime.

2

Personalised self-management support

must be provided to help people with arthritis manage their pain while they wait for surgery.

3

Physical activity programmes

designed to help people with arthritis stay active and prepare for surgery should be actively promoted by Primary Care Networks.

4

Mental health support

should be offered to help every person with arthritis to manage their pain and any associated depression and anxiety.

5

Signposting to financial support and advice

should be provided for people with arthritis in work or seeking work.

6

Covid-19 recovery plans

should address the specific needs of people with arthritis.

In this Versus Arthritis resource guide, we set out what each of these six steps involves. People with arthritis have had to endure waiting for surgery, often in unbearable pain, following more than a year of disruption and delay due to the pandemic. They cannot wait any longer to get the support

they deserve. This guide is intended for Integrated Care Systems (ICSs), Primary Care Networks (PCNs), secondary care providers, public health bodies and social care providers, all working together with local communities and the voluntary sector to deliver these measures.

TAKING URGENT ACTION

Versus Arthritis' Impossible to Ignore campaign is calling for the needs of people with arthritis to be addressed as the NHS restarts treatment and services.

As they wait for surgery, often without a date for their operation, hundreds of thousands of people with arthritis are living with chronic pain. In this guide – developed in consultation with people with arthritis waiting for joint replacement

surgery - we have set out a six-part support plan that must be put in place to improve their quality of life. We cannot leave people with arthritis to live in pain and discomfort without the help and support they need.

Versus Arthritis is calling on local areas in England to put in place this support package for people with arthritis waiting for joint replacement surgery.

CONTACT

If you would like to talk to us about this report, how to implement these recommendations in your local area, or to let us know that you have implemented any of these recommendations, please get in touch with our Policy team at policy@versusarthritis.org

1. CLEAR COMMUNICATION

Clear communication must be provided to people with arthritis about when they can expect to have their surgery and receive the care and services they need in the meantime.

The COVID-19 pandemic has disrupted communication between healthcare professionals and people waiting for treatment. Every ICS in England should ensure that its constituent NHS organisations proactively communicate with every patient on a surgery waiting list. Following NHS England's "Good Communication with Patients: Core Principles' guidance"³, this would involve:

- **Managing expectations:** Patients should be told by their hospital when they are due to have their operation, either after a set amount of time has passed or

whenever there is anything new to say about their care. Each ICS should publish and share information about indicative waiting times for their local population.

- **A single point of contact:** NHS Trusts should provide every patient on their waiting list with the details of a single point of contact they can use to find out more information about their place on the waiting list, advice about managing their symptoms and their options for support while they are waiting.
- **Accessible communication formats and information in a range of languages:** Information should be available to patients in the format and language of their choice (including accessible formats) so all patients can fully understand the information they are given.

- **Information about alternative services and support:** Patients should also be provided with information about the alternative services and support available to them while they are waiting for surgery, for example from the voluntary sector.

- **Highlighting patient safety:** Any communications should clearly set out what kind of COVID-19 related safety measures patients can expect when accessing care, such as protocols for mask wearing or who can accompany them to appointments, so people who are waiting for joint replacement surgery can plan ahead.

"I sat and cried when I was told I'd have to wait so long in this state. There doesn't seem to be any help during this time – you're left in the abyss, not knowing what's happening, living one appointment to the next hoping for good news. It's depressing. There's no support for the impact on your mental health."

Elaine, 55, Sheffield, who has osteoarthritis



2. PERSONALISED SELF-MANAGEMENT SUPPORT

Personalised self-management support must be provided to help people with arthritis manage their pain while they wait for surgery.

The recent National Institute for Health and Care Excellence (NICE) Guideline on chronic primary pain (NG193) recommends that all people with chronic pain should receive a person-centred assessment, be provided with advice and information and should have the opportunity to develop a care and support plan.⁴ Such an approach includes the following elements:

- **Shared decision-making:** Systems, training and resources should be put in place to enable healthcare professionals to support patients to make informed decisions about their health and treatments, taking into account the context of people's lives, and not assuming that there is a single "best"

option suitable for everyone. Support should include local implementation of the Musculoskeletal Decision Support Tools developed by Versus Arthritis in 2020, with funding from NHS England.⁵

- **Personalised care and support planning:** PCNs and GP practices should work together to identify people who are waiting for joint replacement surgery and offer them the opportunity to develop a personalised care and support plan.⁶ The care plan should focus on what matters to the patient, what they would like to change, their goals and the action and support needed to deliver the plan.

Elements of this could include discussion of pain management in line with best practice⁷, access to psychological therapies, physiotherapy where this can be beneficial in building confidence to exercise⁸ and referral to social

prescribing link workers who can connect people to additional support in the community.

- **Taking a holistic approach:** People living with chronic pain from arthritis often experience symptoms other than pain. These problems may not come to light unless people are asked. The Musculoskeletal Health Questionnaire (MSK-HQ) is free to use within the NHS and can help people identify and prioritise areas where they need support.⁹
- **Maintaining a list of resources.** Local PCNs and GP practices should work with people with arthritis and voluntary sector organisations to map national and local community resources, activities, organisations, networks and other groups that can support people who are waiting for joint replacement surgery. The NHSX Digital Playbook for MSK¹⁰ and the BestMSK Innovations Hub¹¹ contain useful suggestions, for example on online pain management resources.
- **Commissioning peer-led support:** ICSs and provider NHS Trusts should offer in person or online peer-led, structured self-management support programmes, including those provided by Versus Arthritis.^{12,13}

"I feel like I'm just a number. There should be support there but they just abandon you, they're interested in helping you and now it is even worse with Covid. If I can't have the surgery, then there needs to be better pain management in place. I do receive medication, but this is far from a cure and I'm still experiencing debilitating pain."

Mykola, 61, East Riding, Yorkshire, who has osteoarthritis.

- **Signposting to health charities such as Versus Arthritis:** The Versus Arthritis website is a valuable source of information and advice which patients can browse, or they can chat to our digital assistant AVA if they prefer. Versus Arthritis also provides face-to-face services and hosts online communities, where people can connect to others affected by arthritis, to share their experiences and provide mutual support. Our free Helpline (0800 5200 520) can provide information and support on a wide range of topics; it is available from Monday to Friday, 9am to 8pm.¹⁴

3. PHYSICAL ACTIVITY PROGRAMMES

Physical activity programmes designed to help people with arthritis stay active and prepare for surgery should be actively promoted by Primary Care Networks (PCNs).

Regular physical activity can reduce joint and back pain by 25% and reduce the likelihood of impairment in walking and daily living activities by a third.¹⁵ The NICE Guideline on Osteoarthritis (CG177) recommends that healthcare professionals *“advise people with osteoarthritis to exercise as a core treatment... irrespective of age, comorbidity, pain severity or disability... including local muscle strengthening and general aerobic fitness.”*¹⁶

Practical advice on how to manage pain or fatigue while exercising should be provided by all healthcare professionals supporting people with arthritis. Within PCNs this is likely to be a combination of

clinical staff such as First Contact Practitioners (FCPs), GPs, link workers and clinical pharmacists. All advice should, where possible, be person-centred around people's preferences for different types of exercise.

There are several helpful resources that primary care teams can use. For example, the Royal College of General Practitioner's (RCGP) Physical Activity and Lifestyle Toolkit has been designed by the RCGP in partnership with Sport England, to be used by primary care professionals working with patients across the UK.¹⁷ The Faculty of Sports and Exercise's Moving Medicine resource for MSK Pain, aimed at people on surgery waiting lists, is another useful tool which healthcare professionals can use when directing or referring patients to supported physical activity.¹⁸

There are many additional voluntary sector physical activity resources

and programmes that PCNs can direct people with arthritis and other musculoskeletal conditions to. These include:

Versus Arthritis Resources

- **Let's Move with Leon:**

Versus Arthritis' free weekly programme of 30-minute movement sessions for people living with musculoskeletal pain. Further resources and content are available on our website and YouTube channel.

Online communities are helpful in providing mutual peer support.^{19,20,21,22}

“I have just started the Let's Move with Leon programme offered by Versus Arthritis – it's great to feel I can actually be guided to exercise with somebody who understands. I definitely felt better after it. I wish I'd found it sooner.”

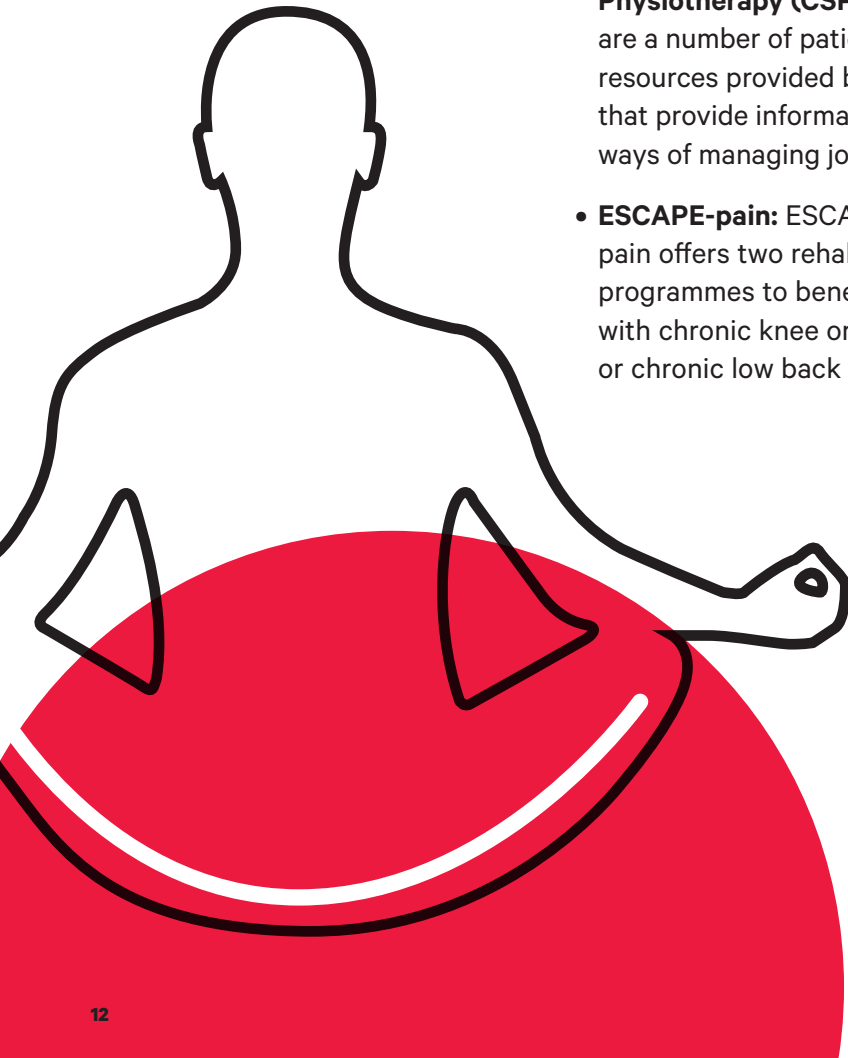
Brenda, 61, Petersfield, who has osteoarthritis



- **Versus Arthritis support groups:**

Versus Arthritis offers a range of support and information to all adults affected by arthritis across England, including physical activities. More information can be found on our website:

www.versusarthritis.org/in-your-area/england/.



Other Resources

- **Arthritis Action:** The charity has an Exercise and Activity Directory which aims to help people with arthritis or mobility issues to find information about activities in their area.²³
- **Chartered Society of Physiotherapy (CSP):** There are a number of patient-facing resources provided by the CSP that provide information about ways of managing joint pain.²⁴
- **ESCAPE-pain:** ESCAPE-pain offers two rehabilitation programmes to benefit people with chronic knee or hip pain, or chronic low back pain.²⁵

- **Good Boost:** A social enterprise that offers rehabilitation programmes for people with a wide range of MSK conditions including arthritis and back pain.²⁶
- **National Rheumatoid Arthritis Society (NRAS):** NRAS provides a range of information and support for people with rheumatoid arthritis.²⁷
- **The Ramblers:** The charity develops health walks which are accessible to people who have

done little or no exercise before and has developed easy access routes for those with reduced mobility, also encouraging people to continue walking after a joint replacement²⁸

- **We are Undefeatable:** A national campaign developed by a coalition of health charities including Versus Arthritis, in partnership with Sports England, to help people with long-term health conditions be more active.²⁹

This is not an exhaustive list. Additional programmes and activities may be available at a local level and ICSs should work with PCNs to identify and map the services that are needed in their area.

These programmes and the professionals running them need to be aware of, and address, the concerns people with arthritis have related to exercise, tackling the common misconception that they need to rest and avoid physical activity.

A useful tool to support localities is the “Providing physical activity

interventions for people with musculoskeletal conditions” report, developed by Versus Arthritis in partnership with NHS England, Public Health England and the Department of Health, which includes a checklist to support the mapping of local physical activity provision.³⁰

To develop local services, grants of between £1,000 and £5,000 are available from the Inspiring Active Communities Fund for programmes targeted at supporting people with long-term health conditions and increasing the availability of physical activity in local communities.³¹

4. MENTAL HEALTH SUPPORT

Mental health support should be offered to help every person with arthritis to manage their pain and any associated depression and anxiety.

Living with chronic pain such as that caused by osteoarthritis is linked to low mood and anxiety. Depression is four times more common amongst people in persistent pain compared to those without pain.³²

The pandemic has also had an impact on the mental health of people living with arthritis. Versus Arthritis' COVID-19 & Shielding Survey of 1,003 people with musculoskeletal conditions, conducted in July 2020, found that 53% of respondents reported difficulties with their mental health due to the pandemic.³³

Similarly, our Impossible to Ignore Survey of 724 people with musculoskeletal conditions in England conducted at the end of

2020, found that 72% of people with arthritis reported their mental health had declined whilst waiting for joint replacement surgery.³⁴

These are the key measures that would help to support the mental health of people with arthritis waiting for joint replacement surgery:

- ICSs and PCNs should work with local people with arthritis and musculoskeletal conditions to co-design, agree and implement clear care pathways for people who have mental health needs related to their arthritis or musculoskeletal condition.
- ICSs and PCNs should review and map local community resources, including working with public health teams to identify local sources of mental health support for people with arthritis and musculoskeletal conditions on surgery waiting lists. This should include voluntary sector sources of advice and support.

- Local health systems should implement the IAPT pathway for people with long-term physical health conditions, developed by the Royal College of Psychiatrists, to ensure people with musculoskeletal conditions are directed or referred to IAPT Long Term Conditions services. Such services should be commissioned locally where they do not already exist.³⁵
- Healthcare professionals should routinely ask people with arthritis and other musculoskeletal conditions about their mental health and wellbeing, as part of a holistic assessment of the patient and developing their personalised care and support plans.
- PCNs should ensure that practitioners, including social prescribing link workers, understand the links between mental health and chronic pain (such as that caused by arthritis and musculoskeletal conditions), and they are aware of appropriate services and other resources to direct people to.
- Healthcare professionals can also direct people to online mental health resources, including those on the NHS App Store or provided by the voluntary sector.

"I've had to put all the things I love to one side, like cooking and baking for my grandkids. My husband has to do everything for me now. I'm helpless. My life is on hold and it's making my mental health very bad."

Christine, 70, Staffordshire, who has inflammatory arthritis



5. SIGNPOSTING TO FINANCIAL SUPPORT AND ADVICE

People with arthritis and musculoskeletal conditions face more challenges than most when it comes to the world of work, challenges that have been exacerbated by the Covid-19 pandemic.

Arthritis and musculoskeletal conditions often limit people's mobility and dexterity and, as we have seen, they can result in people experiencing chronic pain. Every year, these conditions result in the loss of around 28.2 million working days in the UK, accounting for a fifth of all sickness absences.³⁶

In August 2020, our Back Pain Britain survey found that 81% of desk workers who switched to home working had developed musculoskeletal pain and 23% reported that their pain affected them more, or all the time.³⁷

However, with the right support and adaptations, people with arthritis can thrive at work.

Versus Arthritis has published research on two sources of support that can have a positive impact by increasing the independence of people with arthritis: the Government-funded Access to Work scheme; and aids and adaptations in the home. We found that:

- 4 in 5 people who had obtained funding from the Access to Work scheme for equipment to support them in work said that it had improved their working lives^{38,39}
- 95% of people felt their aids and adaptations had some positive impact on their quality of life⁴⁰
- 79% of people felt their aids and adaptations helped them to maintain their independence⁴⁰

People with arthritis waiting for surgery should therefore be made aware of the support available to them to help them return to, or remain in, work from programmes such as Access to Work⁴¹ and they should be signposted to guidance about their right to reasonable adjustments at work.⁴²

Healthcare professionals should also work with social prescribers to ensure that people with arthritis waiting for surgery are signposted to relevant sources of financial, benefits and social care advice, such as available from Citizens Advice and local authorities, when they need it. They should also be referred to the home adaptation services provided by their local authority if they require additional mobility aids or adaptations costing less than £1,000.⁴³

"In October I was made redundant. I'm out of work, quite stressed out about money and concerned about not having a date for my surgery. How do I tell a prospective employer I'm going to need surgery and time off to recover, but I have no idea when? I feel like my life is on hold."

Charmayne, 47, from Oxfordshire, who has osteoarthritis



6. COVID-19 RECOVERY PLANS

Covid-19 recovery plans should include the specific needs of people with arthritis.

Integrated Care Systems have been asked by NHS England and Improvement to develop local recovery plans to maximise elective activity, including hip and knee replacement surgery.

As ICSs develop their recovery plans, there are a number of steps that they can take to ensure that the specific needs of people with arthritis are addressed:

Leadership and strategy

- Include plans to appoint an ICS MSK Lead who will have responsibility for the implementation of the recovery plan and measures in this support package relating to MSK conditions.
- Compile evidence on the prevalence and impact of arthritis and musculoskeletal conditions in the local population. Useful resources include the Fingertips

Tool for musculoskeletal conditions developed by Public Health England.⁴⁴

- Consider how to implement the recommendations of the Getting It Right in Orthopaedics report, such as ringfencing bed space for elective care operations.⁴⁵
- Take into account the emerging evidence on the preferences and experiences of people with arthritis when it comes to virtual consultations and appointments.⁴⁶

Transparency about waiting times

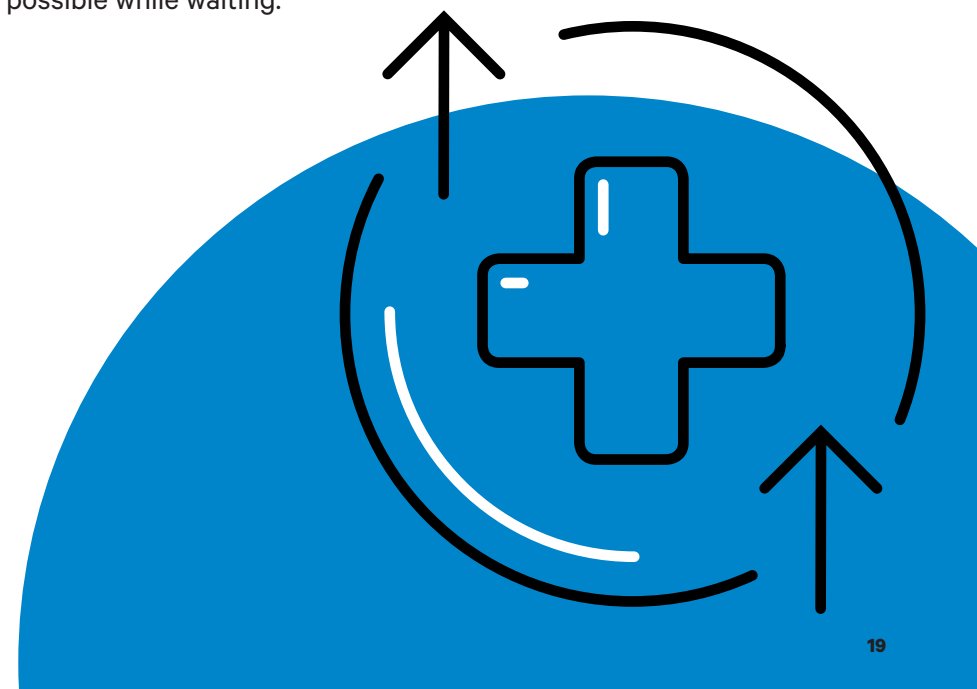
- Publish up-to-date information about the number of people waiting for hip and knee replacement surgery and the length of time that people in both of these groups have been waiting.
- Outline how the ICS will communicate with individual patients about the next steps in their treatment.

Services for people who are waiting for joint replacement surgery

- Map resources for physical activity services and mental health support that can help people with arthritis waiting for surgery.
- Enable work across organisational boundaries, including social care and public health services, to ensure effective planning and delivery of care and support for people with arthritis.
- Outline how people with arthritis who are awaiting joint replacement surgery will be informed about what support is available locally for them to be able to live as well as possible while waiting.

Monitoring and evaluation

- Evaluate the impact of elective recovery plans on addressing pre-pandemic and pandemic-related disparities in waiting lists.
- Plan for monitoring and evaluating the implementation of the recovery plan and the measures in the support package.
- Review recovery plans every six months in line with NHS England and Improvement requirements.



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