

# Supporting young people with musculoskeletal conditions in further education and the workplace

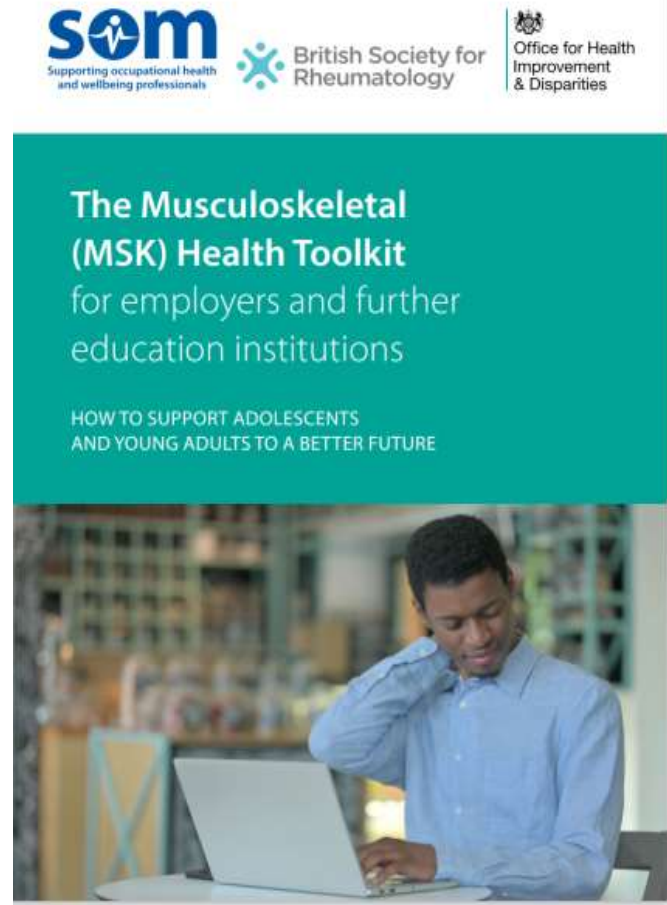
Jacqui Clinch

Consultant in paediatric/adolescent rheumatology  
and persistent pain

Bristol Royal Hospital for Children and Bath Centre for Pain Services

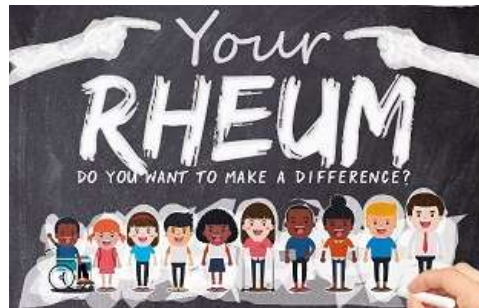
# Overview

- Who does this include?
- Key facts about young people with chronic msk conditions
- Size of the challenge and potential for good
- Young persons voice and experience
- Toolkit
- Discussion



This toolkit was developed by clinical experts, patient representative groups, college and university representatives and, of course, adolescents and young people themselves

**VERSUS  
ARTHRITIS**



**BANNAR**  
the barbara ansell national network  
for adolescent rheumatology



The University of Manchester



British Society for  
Rheumatology



In the UK, 2.8 million people under the age of 35 live with an MSK condition – it impacts their physical and their mental health, and they manage pain and discomfort every day. Around 400,000 have conditions that start before the age of 16.

# Joanna 19 Arthritis

## History

- Diagnosed polyarthritis age 2yrs. 17 joints inflamed.
- Joint injections, surgery , steroids, disease modifiers and biologics
- Physio, psychology, OT constant
- Prolonged initial absence primary school
- Flares in early secondary school (missed 6 months yr10)
- Manages GCSEs and A levels

## Current situation

- Arthritis controlled with biologics
- Enjoys hiking when able and good set friends
- Still some stiffness in morning

Applying to Sheffield uni to study psychology

Keen to follow career in teaching

ON A  
FORM OF CHRONIC JOINT DISEASE  
IN CHILDREN

BY

GEORGE F. STILL, M.A., M.D., M.R.C.P.

MEDICAL REGISTRAR AND PATHOLOGIST TO THE HOSPITAL FOR SICK  
CHILDREN, GREAT ORMOND STREET, LONDON

COMMUNICATED BY DR. ARCHIBALD E. GARROD

Received April 23rd—Read November 10th, 1896

The disease may be defined as a chronic progressive enlargement of joints, associated with general enlargement of glands and enlargement of spleen.



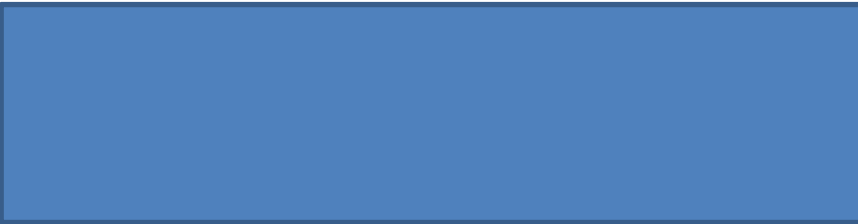
Fig. 1.



Fig. 2.



1997



2022



Knowledge and new therapies have revolutionised outcomes for young people with rheumatological conditions

# Key facts about rheumatological conditions in young people

- More common than you think (1 in 1000)
- Inc JIA (oligo, poly, psoriatic, systemic, AS, ERA), Lupus, scleroderma, myositis, Behcets, connective tissue diseases
- Symptoms fluctuate
- Morning stiffness (if an inflammatory flare) plus generalised joint pain (mechanical)
- Maintaining mobility essential
- Fatigue can be overwhelming
- Mental health often impacted
- Medications alter
- Interdisciplinary rehab invaluable



# Peter 22yrs

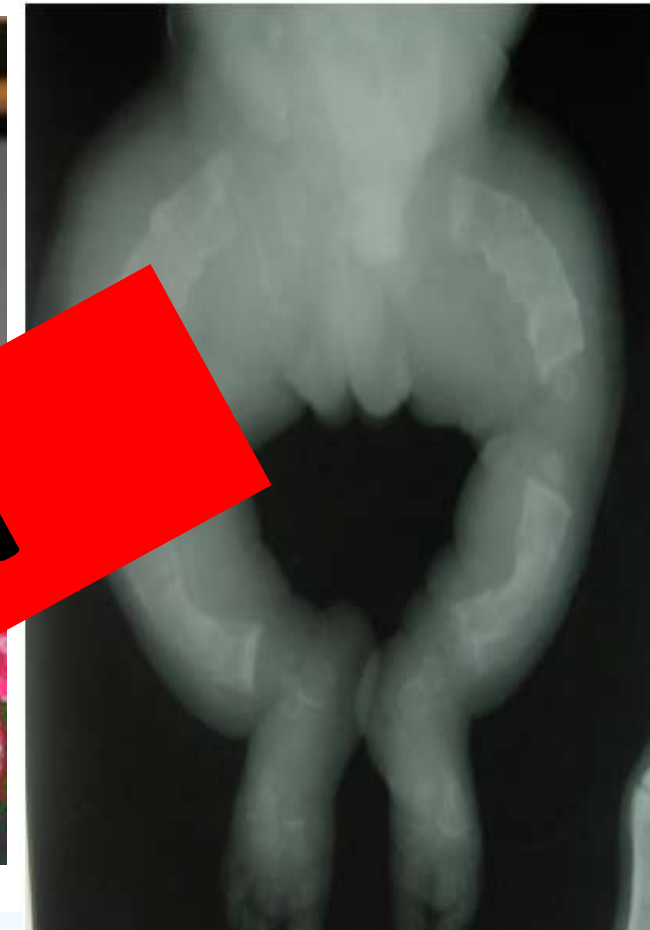
## History

- Diagnosed osteogenesis imperfecta (brittle bone disease) age 6 months
- 7 long bone fractures and 4 vertebral fractures
- Bowed femurs
- 5 orthopaedic interventions (rods)
- Mild scoliosis
- Infusions bisphosphonates 3 monthly
- Interdisciplinary rehab
- Crutches (no wheelchair)
- Family stresses significant
- Peter's mental health poor in adolescence
- Managed uni (engineering) while living at home

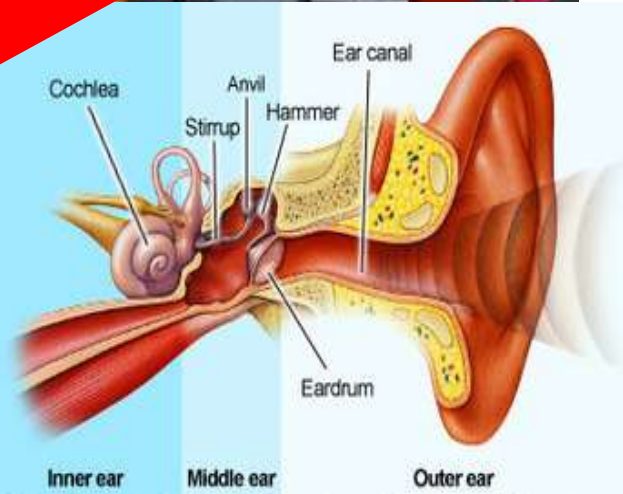
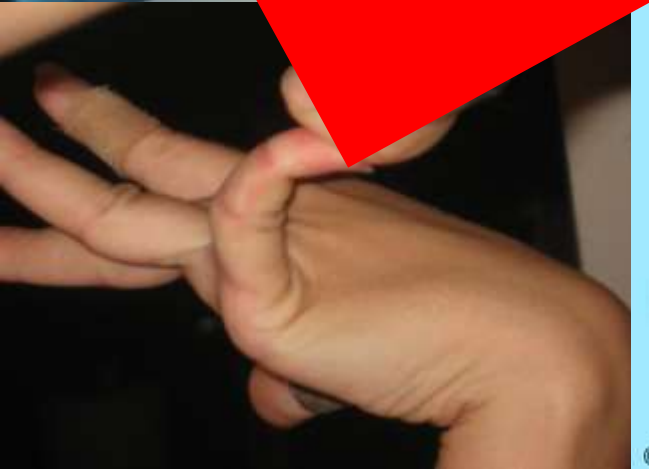
## Current

- Desperate to leave home
- Manages his mechanical pain and fatigue well – some breakthrough pain (hypermobile as part of OI)
- Joined a gym
- Applying for chemical engineering job in Southampton
- Learning to drive





# SPECTRUM



# Key facts about bone disease in young people

- Includes all skeletal problems (including achondroplasia, other dysplasias, brittle bone disease, bone inflammation/infection/malignancy) plus indirect effect of other conditions on bone (inc muscular dystrophy, cystic fibrosis, inflammatory bowel disease)
- Symptoms fluctuate
- Mechanical pain common (particularly loading areas)
- Fatigue (muscle & generalised)
- Mental health often affected
- Surgical interventions
- May continue to require physical aids

# Claire 17

## Primary chronic widespread MSK Pain

### History

- County hockey until 12yrs
- Developed pains knees and ankles
- Pain became widespread.
- Sleep and mental health affected significantly
- Multiple GP & hospital visits
- Home schooled from yr9
- Pain management rehab v helpful

### Current

- V Motivated - pacing
- Sleep still poor
- Fatigue and general pain fluctuates
- Episodes dizziness and nausea persist but manages
- Lives with mum but keen to move

Applying for health and beauty course

# Psychological and behavioural impact of chronic msk pain

Pain assoc anxiety

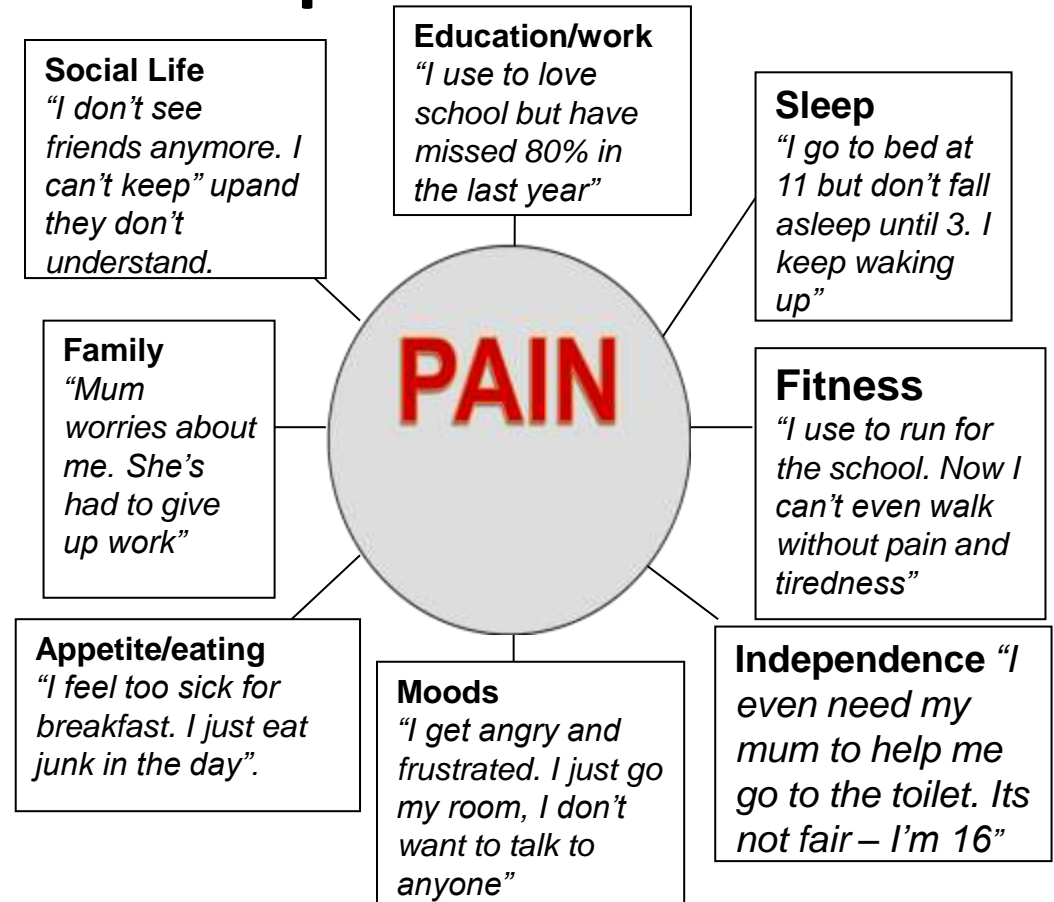
Hypervigilance

Avoidance

Low mood

Catastrophisation

Social isolation

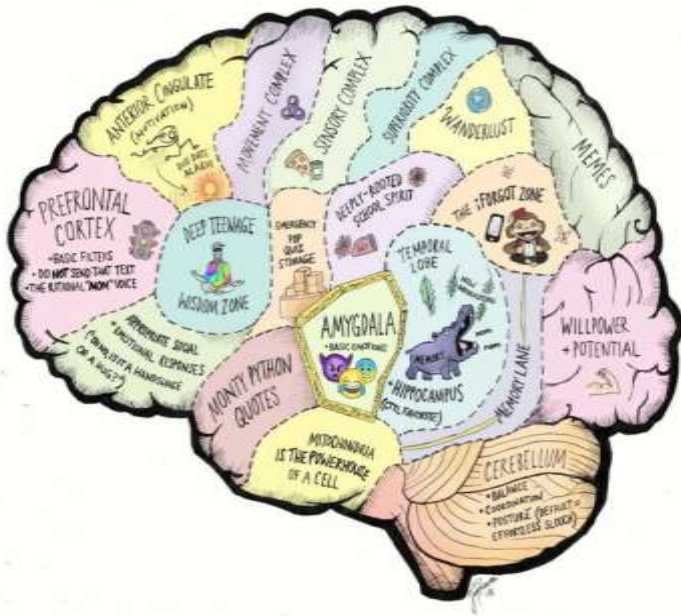


# Key facts about msk pain in young people

- Outlook is very good if pain management intervention early and ongoing rehabilitation supported
- Common

# Developmentally appropriate transition

PARTS OF THE STUDENT BRAIN



- Continues to develop until approx. 25yrs
- Phenomenal neuroplasticity
- Flexibility
- Affected by previous experience
- Although sometimes frustrating, the teenage/young adult brain should be celebrated...



# Why a separate toolkit?

It is crucial to create an environment – whether that be university, school or the workplace – which prevents MSK conditions from developing and allows people who are living with MSK conditions to meet their full potential. Not only does it allow people to thrive and succeed, but it limits the impact that MSK conditions have on our ability to live life exactly how we want to. Ultimately, MSK conditions should not dictate what we want to learn, study or practise and that is why this toolkit is vital for employers and educators to consider. – **Jasmine Davey, young person living with an MSK condition**

***Success – a feeling, experience and accomplishment we all long for in some sense, and often what we search for within education or careers.*** Finding the right environments for success for young people with an MSK condition can be a challenge, but taking the time to address personal needs, adapting to the surroundings and welcoming conversation only opens doors for them to thrive regardless of the difficulties they may be facing. The drive and commitment from young people with these conditions must be accompanied by the dedication from employers and higher education providers to participate in honest conversation about the needs of their employees, understanding how drastically daily life with MSK conditions can change and provide equal opportunity to succeed. The guarantee of this will only encourage young people to find their passions, be fruitful in their roles within companies and flourish as individuals. – **Georgia Bishop, young person living with an MSK condition**

# Aims

1. **Help employers and FE institutions understand the part they play in preventing MSK conditions**
2. **Set out how employers and FE institutions can support young people with chronic MSK conditions to realise their potential, thrive and remain in work or education.**

*This toolkit sets out practical advice for employers and FE institutions to help adolescents and young people maintain good MSK health and help those with existing MSK conditions to thrive in their environment*



## The Musculoskeletal (MSK) Health Toolkit for employers and further education institutions

HOW TO SUPPORT ADOLESCENTS AND YOUNG ADULTS TO A BETTER FUTURE



# MSK wellbeing

Adolescence and young adulthood are key life stages when it comes to establishing health-promoting behaviours which have a longer-term impact on health. There is therefore a window of opportunity to promote better self-care and health for young people, as they take responsibility for their lives through their careers or education.

**A lack of physical activity significantly raises the risk of developing MSK conditions, and those problems can themselves be a barrier to young people being more physically active.**

**Evidence shows that a workplace culture is the most important factor in the success of a physical activity promotion programme. Resources for getting active can be accessed here: <https://www.nhs.uk/better-health/get-active/>**

# IMPACT OF CHRONIC MSK CONDITIONS ON YOUNG PEOPLE

- **Pain**
- **Medications**
- **Fatigue**
- **Reduced mobility and fitness**
- **Altered sleep patterns**
- **Emotional wellbeing**
- **Missed days from work or higher education**
- **Participation in occupation-related tasks**
- **Wider health considerations** – MSK conditions can impact other areas of health such as eyesight and cause uveitis – an inflammation of the eye
- **Isolation, exclusion and stigma** – Living with an MSK can really impact young people's ability to engage and experience a positive work and FE environment. They might feel excluded, stigmatised and isolated because of the difference between them and their peers.

# Opportunity

1. Understanding MSK health
2. Maintaining MSK health
3. Knowledge and training
4. Going further
  - <https://www.youthemployment.org.uk/thegood-youth-employment-charter/>
  - <https://www.gov.uk/government/collections/disability-confidentcampaign>
  - Youth Friendly Employer Badge

For any young person living with a long-term health condition or disability, such as arthritis/MSK, having access to early interventions, support with planning and implementing adjustments, will ensure they are in the best position to successfully complete their course, taking control of their condition as they embark on their career. – **Maureen McAllister, Workplace Health Development Manager, Versus Arthritis**

# MSK HEALTH AND SUPPORT FOR YOUNG PEOPLE IN THE WORKPLACE

*Young people who have a chronic MSK condition may have additional needs that employers should take into account when recruiting and onboarding new staff.*

Taking the time to discuss my illness from the interview stage created open and honest communication rather than feeling it was something that would hinder my progress in the role and I had to hide from my future employers. This led to an understanding that appointments and time away from work were frequent, but I could still be a productive member of the team with this support. Opting for a work-from-home job enabled me to adapt my work conditions for my flare-ups by limiting travel and being comfortable at home, and having flexibility in my day-to-day responsibilities especially when my symptoms were at their most difficult. – **Young person living with an MSK condition**

I always disclose my health condition on my application form for jobs as there is usually some kind of maths/written test during the interview that I require reasonable adjustments for. I usually include some of my experiences as a patient as part of my application for jobs as I feel this demonstrates I can bring a different perspective to the role. My current workplace looked at additional support that could be put in place for me when I had a flare-up to allow me to continue to work. My current role allows me to complete some of my work from home, and be flexible in managing my diary so I can plan my visits, meetings and admin time. I no longer have to handwrite notes as in my current workplace it is all completed electronically. – **Young person living with an MSK condition**

# RECRUITMENT: FAIR AND EQUAL ACCESS TO OPPORTUNITIES

- **Employee Value Proposition (EVP)**
- **Culture** More and more, young people are drawn to culture and values than they are to salary and promotion. This is where you can stand out
- **Job description and advert** Ensure you have clear wording regarding the work environment and equal opportunities for young people and those with long-term conditions
- **Applicants and disclosure** young people are nervous about this. Concerned it affects application and process
- **Adverts** consider placing in different platforms
- **Interview**
- **After interview** early contact with HR

## Access to work scheme

- a grant to help pay for practical support with their work
- support with managing their mental health at work
- money to pay for communication support at job interviews.

<https://www.gov.uk/access-to-work>

# Onboarding

Without good onboarding, a young person coming into an organisation may struggle with a sense of place, belonging, or even a core understanding of their role. Done well, it can serve as an anchor and set them up to thrive in their new chosen career and beyond.

1. Travel
2. Flexible working
3. Communication
4. Signposting
5. Physical adaptation
6. Mental health support
7. Strategies for planned and unplanned absence
8. Expect and accept change



# Impact

‘When I started the role, I was placed in the refrigerator section of the store. However, I found that this area was really cold, and it was starting to affect my joints. Being cold made it difficult for me to place things on the shelves and to reach items down low or up high. I spoke to my manager at the store and told them about the difficulties I was having working in the fridge section. They asked me what area I would prefer to work in; I said I was happy to work anywhere other than the fridge or freezer areas. My manager was great and took on board how temperature can affect me and my condition. They moved me to the bakery section, as this area was warmer than the rest of the store – it also smells great! It was a lot easier for me to work in this area of the store and I found my joints were not affected as much. This small change made a big difference to me being able to continue with my role’

I found the shift pattern very physically demanding with my arthritis. At the end of a long shift, I struggled with pain and fatigue. I also struggled with handwriting notes. I decided I needed to seek support and ended up speaking to my manager and getting a referral to Occupational Health. They were able to put in adjustments for me such as working more frequent, shorter shifts instead of longer ones. I could split my break up so instead of having one full-hour break, I had two half-hour breaks throughout my 12.5-hour shift. I was able to work some of my shifts in less physically demanding areas. I’ve worked with supportive bosses. My condition was never a factor. And, crucially, they let me develop a work-life balance that fitted around what I was physically capable of doing. They showed faith in me, and I repaid them with hard work. I was able to survive and then thrive in employment.

I told my employers I could only work part-time because of my hospital appointments and that I couldn’t work for long periods of time. I got referred to Occupational Health, who then helped my employer understand my conditions more and how they could help. For example, after that, I got extended breacktimes

# PREPARING YOUNG PEOPLE FOR ENTRY TO FURTHER EDUCATION

*Applying to FE when you are a young person with an MSK condition often comes with as much excitement as it does reservations*

All the evidence shows that, in a supportive and flexible learning environment, young people with MSK conditions thrive both educationally and socially.

## *Pre-application details are important*

- Inform students about health and wellbeing support services available on-site. This includes signposting to financial support such as the Disabled Students' Allowance (DSA)
- Make consent and information sharing policies clear from the outset (pre-application) so young people know exactly what happens with their disclosures and personal information
- Ensure there is specific information available – such as a subsection for young people with MSK conditions within the recruitment process. It is helpful for individuals to feel seen and catered to from the off.
- Provide a dedicated liaison person who can confidentially answer other questions that may include signposting to relevant resources and organisations. Having a specialist assures potential students of your understanding of them and your commitment to supporting them.

# Starting strong

- Communication
  - Disability services, support and wellbeing, teaching staff, home health service
- Enable
  - Personal tutors, academic advisors – early signposting
- Flexibility
  - Ideally avoid last minute adaptation
- Work placement
  - Focus on positives
- Financial
  - Often have added financial burden
- Disclosure
  - Tricky and complex
- Peer to peer initiatives

# Starting strong

- Physical – disability access plans, gyms, timetabling etc
- Accommodation
- Medication management
- Mental health support
- Pain and fatigue support – flares, sleep, counsellor access etc
- Exams and assignments

The most effective support I have received both whilst a student at university and in my early career has come from having open and honest conversations with the people around me about my needs and the reality of living with arthritis. Support from universities at the enrolment stage is vital for discussing appropriate accommodation such as ground floor/adaptations, conversations with tutors around options for extensions if deadlines are affected by flare-ups or hospital visits and planning your day around medications if side effects are a struggle. – Young person living with an MSK condition

# Impact

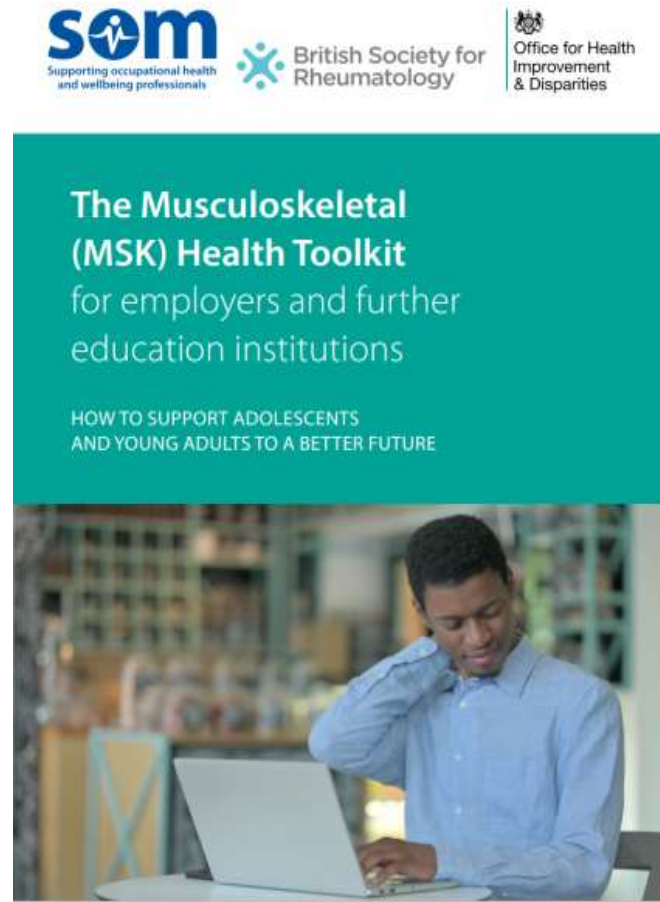
JIA impacted on me at university in a different way than I thought it would. Other than the typical physical pains from flare-ups or previous joint damage, the mental health aspect reared its head. It finally dawned on me what effect arthritis was going to have on my life. Thanks to my mentor I was able to discuss emotions like these, and through discussions with the university, I was allowed to take the rest of the academic year off to work on my mental health and come back next year. Having a mentor at university as a person with an MSK condition is, in my opinion, one of the best adaptations you can have. My mentor helped explain my JIA's current status to lecturers, ensured I was getting everything I needed disability-wise and helped me to keep on track with coursework hand-in dates. I don't think I would've made it without her

During my undergraduate degree I was assigned a one-to-one mentor for those with conditions that would affect their university life and learning. My mentor was crucial to my success; without her, I would not have completed my degree. In my first year, I struggled as an 18 year old who was independent for the first time, whilst also trying to manage my juvenile idiopathic arthritis (JIA). She not only assisted me with time management and organisation of my university work but also with tough social circumstances and extreme social anxiety. My mentor was also very helpful in conveying my arthritic needs to the university. Lecturers took her more seriously than they did me – some believed I was playing upon my disability. My mentor was crucial in helping me get the deadline extensions and support from the university that I needed to finish the degree.

# Next steps

- Share widely
- 6<sup>th</sup> form colleges, universities, business platforms
- Adolescent health services
- Prospective feedback from young people
- **Success stories**

Jacqui.clinch@uhbw.nhs.uk



# Reference group

**Jasmine Davey, Amy Donaldson, Georgia Bishop, Natasha Shaw** Toolkit Youth Advisors, Versus Arthritis

**Nuzhat Ali** Musculo-Skeletal National Lead, Joint Work and Health Unit, Department of Health and Social Care (DHSC)/Department for Work and Pensions (DWP)

**Dr Jacqui Clinch** Consultant Paediatric and Adolescent Rheumatologist, Bristol Royal Hospital for Children & Bath Centre for Pain Services; Vice President, British Society for Rheumatology

**Dr Janet E McDonagh** Clinical Senior Lecturer in Paediatric and Adolescent Rheumatology, Centre for Epidemiology Versus Arthritis

**Lynne Woolley** Head of Young People and Families Service at Versus Arthritis

**Sue Brown** CEO ARMA (Arthritis and Musculoskeletal Alliance)

**Professor Suzanne Verstappen** Professor of Epidemiology, Centre for Musculoskeletal Research, The University of Manchester

Claire Pidgeon Occupational Therapist, Birmingham Women's and Children's NHS Foundation Trust

**Dr Elaine Wainwright** Lecturer in MSK Health Epidemiology Group, University of Aberdeen

Monica Acheampong Regional Health Improvement Manager, DHSC

**Annie Diamond** Regional Health Improvement Manager, DHSC

**Kathryn Robinson** Senior Policy Officer, Joint Work and Health Unit, DHSC/DWP