

**WFH COVID-19 Webinar:
Maintaining Joint Health for People with Bleeding Disorders During COVID-19
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IMPACT OF THE PANDEMIC ON JOINT AND MUSCLE HEALTH

Greig Blamey, BPE, BScPT, CHT

For many people under lockdown during the COVID-19 pandemic, decreased physical activity has had negative impacts on their joint and muscle health. However, there have been some benefits.

Joint health

- One of the indicators of bone health is bone density. Maintaining a weight-bearing regimen is important to building and maintaining bone density. A decreased level of weight-bearing activity for a period of a few weeks would have negligible impacts. But over a period of many months, there may be measurable changes in bone density in individuals who have not been maintaining weight-bearing activities and exercises.
- However, for those with conditions such as chronic arthritis or joint damage in the weight-bearing joints of the ankles, knees and hips, the decreased level of activity and enforced rest imposed by lockdown restrictions may possibly have brought some benefits.
- For soft tissues in the joints such as the joint capsule, synovial lining of the joint, and ligaments within the joint capsule, there may likewise be some potential positives and negatives. Many people with hemophilia have chronic synovitis – thickened synovial lining caused by multiple bleeds. For those under COVID-19 lockdown, more time at home, resulting in more rest and less impact to the joints, may result in improvement of their chronic synovitis.

Soft tissues

- One of the important aspects of soft tissue joint health is proprioception, which refers to sense of position and the ability to control our body dynamically as we move, enabled by nerve receptors located in the joint capsule. Much of that skill comes from practiced and regular use. Proprioception is important to maintaining our balance when we are out and about, walking on uneven surfaces or through crowds and changing directions to avoid collisions with other people – negotiating such challenges to our balance regularly helps keep it healthy. Over the course of several months under lockdown, these skills may be somewhat at risk.

Muscles

- For most people, being under lockdown has been detrimental to the muscular tissues in terms of strength, flexibility and endurance. Being more sedentary, using the muscles less, and not

engaging in a home exercise program over a course of weeks is generally not a problem – but prolonged decrease in activity over the course of several months will lead to a decline in strength.

- Flexibility of the muscles, particularly those surrounding the knees and elbows, also declines with lack of regular physical activity and exercise. With more sedentary lifestyles at home, the elbows and knees may get less exercise and be fully extended less frequently. It is important to look out for slow and insidious loss of muscle ability to reach full extension over a long period of time, particularly those surrounding the knees and hips.
- Muscle endurance refers to the ability to perform tasks over and over again, therefore for those who are less active due to COVID-19 restrictions, the longer the pandemic continues, the higher risk there is that muscular endurance will degrade.

Impacts of COVID-19 pandemic

- The impacts of the pandemic are not the same in every part of the world. Lockdown has not been the same for everybody. In many countries, critical sectors and certain job categories are classified as essential services – in the health sector, physicians, nurses, physiotherapists, and other healthcare providers are deemed to be “essential workers.” Workers who deliver essential services have continued to do their jobs provided they have no symptoms of COVID-19 infection.
- Workers all along the food supply chain have also been essential during the pandemic: farmers, food processing workers, food distributors, market sellers, grocery workers, etc. Many essential workers have been working harder and longer days than usual during pandemic, and may be getting plenty of exercise or possibly exacerbating pre-existing symptoms such as arthritis.
- For people with bleeding disorders who have been more sedentary under lockdown and are emerging at decreased levels of fitness, it’s important to resume activities gradually and safely so as not to provoke old injuries or create new ones.

HOME-BASED EXERCISES – TIPS FROM THE FIELD

Pamela Narayan, BPT, MSc Physiotherapy (India)

- These exercises are general tips on ways you can exercise at home and are not intended to be prescriptive. Consult your physical therapist or hemophilia team for advice on what’s right for you. Be very careful when you start to engage in an exercise program, particularly if you do not have access to clotting factor.
- The demonstrations are assisted by a 20-year-old student with severe hemophilia recovering from recent elbow bleeds. While he has occasionally received low-dose prophylaxis when clotting factor is available, his musculoskeletal problems are mostly managed with physiotherapy.
- The demonstrations consist of:
 - A simple workout for strength, flexibility and core function; and
 - simple static elbow exercises, which one can use after bleeding has stopped and while the injury is resolving, to gradually ease into exercising the elbow.

Warm-up

- This warm-up routine can be used by patients with mild/moderate/hemophilia with mild joint disease and by people with severe hemophilia. Some of the exercises can be augmented into strength exercises by using a small sandbag (e.g., 250g sandbag) or resistance bands.

- **Move mindfully and not mechanically:** focus on your joints and muscles as you move – this makes exercise much more effective. These movements should be done gently and slowly, about 5-7 times per routine. Make sure you have space to perform the exercises safely, and make sure your movements are within your abilities.
- In this demonstration, the student started in a standing position with his hands loosely at his sides.
- **Head/neck rolls:**
 - Gently lean your head forwards and backwards.
 - Lean your head (ear to shoulder) from side to side.
 - Turn your head (chin towards shoulder) from side to side.
 - Drop your chin to your chest and roll your head in circular motions sideways, backwards, around to the other side and to the front. Repeat in other direction.
- **Shoulder rotations:**
 - Move your shoulders up and down.
 - Square your shoulders and pull them up and back, then release.
 - Rotate your shoulders in circular motions forwards then backwards.
- **Arm rotations and exercises:**
 - Raise your arms pointing upwards and make circular motions forwards then backwards.
 - Extend your arms horizontally on each side and parallel to the floor, stretching as far back as comfortable; swing them forwards so that they cross into an 'X' in front of your body and then back to the extended horizontal position.
 - Swing your arms up and down/forwards and backwards simultaneously but in opposite directions of each other.
 - Keeping your elbows close to your sides, raise and lower your forearms towards and away from your body in weight-lifting motions.
- **Wrist rotations and exercises:**
 - Extend your arms in front of you and parallel to the floor and rotate your wrists in circular motions, then rotate in opposite direction.
 - Extend your arms in front of you and parallel to the floor, palms down, extend your fingers straight then close each hand into a fist.
- **Torso bends:**
 - Bend your body forward at the waist and reach towards your toes (it is not necessary to touch them), then straighten back up.
 - With your hands on your hips, lean backwards then straighten back up.
 - Lean sideways, your hand reaching down to your knee as far as you can comfortably, then straighten back up. Repeat on the opposite side.
 - Rotate your upper body from one side to the other.
- **Hip rotations:**
 - With your hands on your hips, rotate your hips in circular motions in one direction then the other.
- **Knee rotations:**
 - With your hands on your thighs, rotate your knees in circular motions in one direction then the other.
- **Leg lifts:**
 - With your hand resting on a stable surface for support, swing one leg backwards and forwards. Repeat with other leg.
 - With your hand resting on a stable surface for support, lift one leg from side to side. Repeat with other leg.

- **Ankle rotations:**
 - With your hand resting on a stable surface for support, rotate your ankle in circular motions in one direction then the other. Repeat with other ankle.
- **Sit and stand exercises:**
 - With arms crossed over upper body, standing with both feet on the ground, sit down on a chair and stand up again.

Static elbow exercises

- After acute bleeding has stopped and as the injury resolves, range of motion begins to return to the elbow and is usually in the middle range after 3-10 days. Before re-starting exercises, it is important to make sure that the swelling has gone down; there should be no warmth around the injury and pain score should be around 5 or less. This is a good stage for isometric/static exercises, which involve no movement of the joint – they consist of contracting and releasing the muscles around the joint.
- **Static scapular exercise:**
 - Lying down on your back with your elbows at your sides, raise your forearms perpendicular to your body (at 90 degrees) with palms facing upwards, push your shoulders back against the surface, hold for 5 seconds and relax.
- **Static biceps exercise:**
 - Raise your forearms in weight-lifting motion towards your body (at 90 degrees) then place a hand on the lower third of the other forearm and push downwards while simultaneously pushing back with the forearm and contracting the biceps for up to 5 seconds, then relax.
- **Static triceps exercise:**
 - Hold your elbow in your hand and push downwards while simultaneously using your hand to push back upwards and contracting the triceps for up to 5 seconds, then relax.

TELEMEDICINE – BEST PRACTICE AND PRACTICAL TIPS TO BE MOST EFFECTIVE

Cesar Haddad, physiotherapist specialized in hemophilia care (Lebanon)

- During the COVID-19 lockdown period, many people were obliged to stay home except for specific urgent situations. This has made it very difficult to continue our daily routines and activities. For many people with bleeding disorders, lack of exercise created more problems – weaker muscles, more joint pain, stiffness, and even impaired function.
- Healthcare professionals have had to find ways to adapt to this new situation and continue being functional while restrictions are in place against non-essential travel. Many have introduced telemedicine – healing from a distance – for consultations and follow-up to continue to provide access to care and keep patients motivated to adhere to their rehabilitation protocols.
- The criterion and main purpose of telemedicine is to provide clinical support and improve overall health outcomes. The main aim is to overcome geographical barriers. Telemedicine can be passive, for example, watching videos on the Internet – but it's very important to know how to perform the exercises correctly and that they are appropriate, otherwise they can be detrimental to the joints and musculoskeletal health. Telemedicine can also be interactive, for example, video-calling or online chat – this allows the patient to explain their concerns and problems and the healthcare professional to then develop a rehabilitation program accordingly.

- In some countries, telemedicine can be difficult due to limited internet access or power outages. Telephone consultation is possible instead but it not as effective as video-calling in which the physical therapist can see and guide what the patient is doing.
- Online consultation is indicated for people who are in self-isolation, have COVID-19 symptoms, are at high risk of infection, and/or have complex medical or health conditions. In addition, it is useful for people with joint problems and mobility issues, and those far from treatment centres.
- During an online consultation, the healthcare professional will ask about the patient's medical history, frequency of bleeding, sites of bleeds, treatment regimen, and musculoskeletal target joint status. The patient may be asked to demonstrate their range of motion, strength, flexibility, etc. It's very important to discuss whether the patient has musculoskeletal pain, when and how often it occurs, and levels of pain they experience with different activities so that the healthcare professional can tailor the exercise program accordingly.
- Online consultation involving physical therapy exercises is not recommended for patients with high bleeding tendencies who do not have clotting factor concentrates at home, nor patients with joint inflammation or health conditions; in such cases, face-to-face consultation is advised.

Tips for healthcare providers

- Telemedicine involves a new way of thinking and a new approach to care. Healthcare providers are not able to use their hands for touch and palpitation as part of clinical assessment. It requires strong patient evaluation, education and communication skills from a distance.
- It is essential to listen carefully to the patient's concerns and needs, explain diagnosis and treatment options, and adapt to their needs. Telemedicine sessions should be interactive, with both the healthcare provider and patient participating in discussions and decisions.
- Healthcare providers must ensure confidentiality and privacy of patient information, in accordance with local laws and regulations.

Practical tips for people with bleeding disorders

- Make sure that good technology is in place. If using a mobile phone or laptop for a video call, make sure that the software is up-to-date and the hardware has adequate capacity. A good internet connection is important for you to be able learn and follow the instructions and for the physical therapist to be able to watch and guide what you are doing to prevent injury or damage.
- Make sure there is ample space for doing the exercises.
- Know and respect your limitations. It's very important to keep in mind that not all exercise videos are suitable for people with bleeding disorders – it's different for each person. Some exercises may need to be adapted to your capability. It's also important to remember not to over-exercise following an extended period of inactivity.

Telemedicine challenges

- The telecommunications and electricity infrastructure in developing countries are sometimes insufficient for telemedicine. In addition, some therapists are resistant to using such technologies. Other barriers include language and cultural differences, which may be more challenging in online consultations than face-to-face. There are also laws and regulations that must be followed.

- The use of telemedicine also demands major changes to organizational roles and rethinking of the delivery of clinical services, particularly because physical therapists cannot use their hands to perform musculoskeletal assessments. There must also be detailed and careful evaluation of new practices to ensure patient safety and effective outcomes.
- Contact your healthcare provider or treatment centre for information about whether telemedicine consultation is available and appropriate.

“STUCK AT HOME” CHALLENGES FOR PATIENTS

Andrew Selvaggi, Personal trainer, Melbourne, Australia

- This is a snapshot of my life for the past 6 months here in Australia while we've been dealing with the COVID-19 pandemic. I'm 33 years old from Melbourne. I'm a patient with severe hemophilia A and I have chronic persistent inhibitors. I'm a qualified personal trainer and also a senior project manager at the University of Melbourne. At age 20, I was in wheelchair, then I lost 30 kilograms and was able to get up and walk around. I have had two total knee replacements, both my ankles fused, six major orthopedic operations, and chronic arthritis in my old target joints. My treatment program for the last four years has been Hemlibra (emicizumab).
- Australia's COVID-19 caseloads are relatively low compared to some other countries but our population is quite small. We had nationwide lockdowns from late March to May then state-based easing of restrictions in June. Unfortunately, we have had a quite aggressive second wave in late June leading to further state-based lockdowns for a minimum of six weeks including in the state of Victoria, from July 9 to August 20. We've had a large increase in community transmissions and the lockdowns have been harsher the second time around compared to the first time.
- Our daily case rate is about 28 per million compared to about 213 per million in the United States; about 10 per million in Canada; and about 36 per million in India. Australia's unique in that it's a quite large country. My state of Victoria is the mainstay of where all the cases are occurring – with a population of about 6 million, the state has about 113 cases per million. COVID-19 is taken very serious here and leading to quite harsh lockdowns.

Lockdown 1.0

- The two lockdowns for me they have been completely different. Our first lockdown was a sudden sweeping lockdown. As soon as we got a couple of cases here, the borders were shut and everyone was put under restrictions to stay at home and permitted out only to go to the shops for food and essential goods and services; with the exception of essential workers. There were some nice gains early on from inactivity; but in the long term, there have been a lot of disadvantages.
- In Australia, all the gyms and parks were closed. Bike riding was permitted only within a very limited area of where you live. Among the only ways to go outside for exercise was to go out for a run. This is impossible for me because of my fused ankles and knee replacements, so that left me at home. For the last 10 years, I've been working as a fitness instructor but I've never had a home gym. I'm speaking from home gym now – this is the result of the second lockdown. I have always relied completely on external gyms. And most across the world, all shops had sold out of all equipment as soon as they began to shut things down.
- My baseline is usually 10,000 steps per day; under lockdown that dropped down to about 2,000 steps. My activity levels dropped to non-existent; my activity tracker showed that for range of activity and times spent standing, walking, and exercising, I was not hitting my marks every day in April.

- The first 4 weeks of lockdown were great – joint swelling went down, movement felt better, niggles weren't happening anymore. Then at around 5 to 12 weeks, my joint mobility and function suddenly and rapidly decreased. My joint pain came back and getting out of bed was a task. My diet, sleep, and self-awareness/proprioception varied day to day. I also had mental and relationship strains; I was working from home and anxiety levels were high.

Lockdown 2.0

- In late June, lockdown was lifted and the gyms reopened but 10 days later everything closed again with a second lockdown. After 10 days back at the gym, I had started to feel better and had more energy and my motivation levels were high.
- Going into the second lockdown I challenged myself – keep motivated and keep on moving. So I set myself a 6-week lockdown challenge to come out more fit than I was 10 years ago. Being stuck at home, I kitted out a home gym and I focused on spin/exercise biking, cardio workouts, and functional bodyweight exercises.
- The use of a fitness and activity tracker has become really powerful for me – it lets me track my movement and log my daily physical activity to see if I've been active enough. I do two workouts a day and use a spreadsheet to track my daily activities, including duration, heart rate, calories, and type of exercise, and I take a daily photo to see how my body is tracking. I keep graphs on my average heart rate and peak performance. Logging this information daily is a powerful tool – it's like a treatment diary only I have an exercise diary as well.

Results and advice

- It's important to keep active at all levels, whether it involves getting out of bed earlier or going for a walk outside up and down the street. If mobility is an issue, do what you can within your body's means and based on your fitness and mobility levels. The use of resistance bands can be helpful for exercising specific areas parts of the body.
- I found that keeping active resulted in an increase in joint function and decrease in arthritic pain.
- For me, any movement was better than no movement; so I would pace, take the long way around to walk to another part of my home, for example, go to front door and back. It resulted in better sleep and better routines – often, when you're more active, you're more conscious of your diet and weight management and keeping actively healthy.
- My stress levels went down and I noticed that I was more focused and more productive while working from home. My mood and relationship at home has been a lot better since my life is more balanced.

QUESTION & ANSWER PERIOD

I have frequent shoulder bleeds. I started to do isometrics but have bleeds again. How do I correctly measure the appropriate amount of exercise vs. the risk of bleeding? How can people who do not have factor coverage do the exercises without the risk of bleeding?

- Bleed recognition is a critical skill that everybody with hemophilia must have. Contact your hemophilia team anytime to go over the signs and symptoms of actual bleeding. Shoulder bleeds are not very common. If bleeding occurs during exercises, it's important to understand what's happening.

- Joint or muscle exercises should not provoke increased levels of pain while you're doing it or immediately after. Extended periods of exercise may cause muscle soreness. But If exercising provokes significant spikes in pain, stop what you're doing and contact your hemophilia team to go over what you're doing and whether it is the right exercise for your current musculoskeletal status.
- For people with limited access to clotting factor, re-bleeding often occurs if they do not give a joint or muscle the proper amount of rest after a bleed. It is very important to give time for the tear inside the joint to heal completely before restarting an exercise program or regimen. The return to activities, even static exercises, has to be gradual and progressive.

Is the use of pain medications during physical therapy recommended?

- No – it is risky to use pain medication specifically as part of a physiotherapy program or to be able to perform your exercise routine. This is dangerous because you may be masking a built-in biological warning sign that something could be wrong. However, it's a different consideration if the pain medication is for a purpose other than physiotherapy or exercise; or after joint replacement and with high levels of prophylaxis, as part of physiotherapy to restore joint motion.

Many people under COVID-19 lockdown have been restricted at home and less mobile for several months. Has allowing a target joint to rest over this extended period had beneficial effects?

- Some of the common reasons given for not resting a target joint include having to go to school or work so a lockdown is an opportunity to allow chronic injuries and target joints to rest. But when lockdown ends, after an extended period of rest, it's critical to return to activity in a gradual way. Overall, while resting a target joint, it's good to keep the rest of the body active.

There are many exercise and workout videos available via YouTube and other websites that are for people who do not have hemophilia. Can they be used or tailored by people with hemophilia?

- People with hemophilia should work in collaboration with their physical therapists to make sure exercise routines and regimens are appropriate. For example, they can look for videos that interest them and consult with their therapist or hemophilia team to make sure they are suitable.
- While Internet videos are useful in providing instructions on how to do specific exercises, many people often try to go beyond their capabilities with exercises that are not suitable to them. There is a plethora of resources available – it's good to get your physical therapist or hemophilia team's endorsement before starting new exercise routines. Always respect your body's abilities and limitations and stop at any sign of pain.

What is suggested to maintain activity and mobility for young children around 2 to 4 years of age?

- It's hard to get very young children to do routine exercises. For children that age, the focus is hitting developmental milestones and activity and exercise through play. During lockdown, while children are restricted from going to school, daycare, and parks, it's important to carve out time to make sure they get the opportunity to play and be active. It is also important to regularly assess your child and contact the hemophilia team if there are any signs of injury.

I sometimes experience numbness or electrical shock sensations in my legs after sitting for a long time – what should I do?

- A lot of time spent sitting causes sustained spinal pressure through the vertebral discs and nerve roots. Changing positions regularly is key to maintaining tissue health. Those working from home might consider a standing desk. A comfortable chair that provides good support is also important.
- It is also important to take breaks to move around and get some exercise. For example, you could set your alarm to take regular breaks to do 5 minutes of exercise.

How should people with hemophilia who have target joints approach trying to regain mobility and strength without causing increased bleeding?

- Many people with access to clotting factor return to their normal activities as soon as the pain is gone but then have re-bleeding. It's very important give a joint bleed a lot of time to heal. The length of time needed will depend on the amount of blood in the joint cavity; it may be two days for a small bleed or longer for more serious bleeds. After bleeding has stopped and the healing process has started, rehabilitation can begin slowly to restore flexibility, strength, and range of motion – but it must be a gradual process to avoid re-bleeding or new bleeding.

Is it safe to use protein supplements for muscle building?

- Before starting any protein supplements, it is important to consult a healthcare professional to have the nutritional information checked because some products contain anticoagulant properties.

Do fish oil and garlic inhibit coagulation?

- Consumption normal amounts of garlic does not inhibit coagulation. Fish oil should be taken by people who at risk for thrombosis and those who have elevated lipids and triglycerides; there aren't any significant concerns about inhibiting coagulation.