Portsmouth Hospitals NHS



**NHS Trust** 



### Department of Rheumatology

# Dam it Arthritis

Dads And Mums living wITh Arthritis

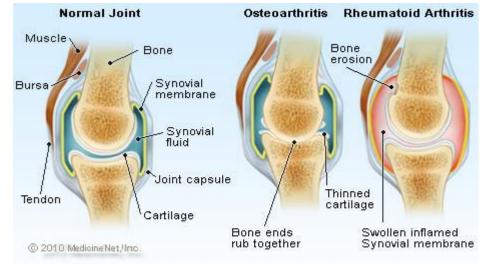
Dads and Mums with Arthritis – DaM it Arthritis – is a local support programme aimed at supporting parents living with any form of arthritis and connective tissue disease – those aspiring to be parents, their families, friends and those working with them.

The programme of support offers drop-in meetings and family events which will enable people to access information, advice and support, helping them to self-manage their arthritis and connective tissue disease whilst managing a busy family, work and social life.

The meetings also provide **Dads and Mums** and their families with an opportunity to access peer support and share experiences, reducing anxieties and frustrations.

#### Remember - not all arthritis conditions are the same

Osteoarthritis is the most common form of arthritis affecting about 3.3% of the population. Associated with those over 60 years old, Osteoarthritis (OA) is a type of wear-and-tear joint disease that results from breakdown of cartilage and underlying bone.



## Normal and Arthritic Joints

### Inflammatory Arthritis is

an autoimmune disease that causes inflammation in your joints and body tissue. It's the second most common form of arthritis in the UK. Inflammatory arthritis causes inflammation in the joint, causing it to become painful, stiff and swollen, restricting the range of movement. In addition the disease itself can cause significant fatigue and general feeling of being unwell.

The term **Connective Tissue Diseases** covers a wide range of autoimmune diseases. They are often associated with specific auto-antibodies which can help define the diagnosis. Management of these conditions concentrates on controlling inflammation and preventing damage to vital body organs and joints, muscles and bone, with most conditions responding well to medication such as immunosuppressants, which reduce the activity of the disease and dampen down an overactive immune system.

#### The testimony of Jenny, a 35-year-old with 2 children and Rheumatoid Arthritis

"Although I do my best to function like a "normal person," I know that my Rheumatoid Arthritis has an impact on the rest of my family. My husband often has to take on some of the household duties when I have a flare, with more joint pain and stiffness and fatigue"

"What I worry about the most, though, is the effect that my Rheumatoid Arthritis has on my children. I was once told "Parenting is the hardest job in the world even if you are doing it right." Sometimes it feels like "doing it right" is almost out of reach for me.

Inflammatory arthritis and connective tissue disease are typically diagnosed between the ages of 20 and 50 (parenting age range); therefore clearly there are many children in a family affected by these conditions.

Research shows that there are also psychological effects of living with a chronic disease. Life stressors seem to have a much greater negative impact on the whole family, perhaps magnified by persistent thoughts by parents that they are not living the lives that they imagined for themselves or that their parenting is not the parenting that they wanted.

What does this mean for the children of parents with arthritis and connective tissue diseases?

- Children can experience stress caused by worrying about the health of the parent with arthritis and connective tissue diseases and what disease progression may mean for the family.
- It can be time-consuming to help parents with household chores, as well as the parent's own daily activities in some circumstances.
- Children at all ages can be expected to help with cleaning, shopping, cooking, babysitting and helping younger brothers and sisters with homework.
- If parents need help with their own personal hygiene, it can be an additional physical and psychological burden on children.
- The child's social life may be impacted negatively if they are apprehensive about bringing friends home, due to his or her parent's disability.

The DaM-it Arthritis Project aims to support parents

- To be honest with their children about the arthritis and connective tissue disease, as soon after diagnosis as possible. This allows the whole family to cope a team, and avoids the situation where the child feels isolated when they find out later.
- Get social support for the parent with arthritis and connective tissue disease either via a formal or friend network whilst keeping active and reducing stress.

For more information about DaM-It Arthritis- **please contact** Colin Beevor, Matron and Service Manager, <u>colin.beevor@porthosp.nhs.uk</u> 023922864142.