

Paquet's
Association



My Paquet's Passport

Version 1

Paget's Disease of Bone

Throughout life, normal bone repairs and renews itself (bone remodelling). Paget's disease, however, is characterised by abnormalities in this process.

Under normal circumstances, the amount of bone broken down is balanced by the amount of new bone that is formed. In Paget's disease this process is disrupted and rapid. The affected bone has an abnormal structure and is often enlarged and misshapen.

Paget's disease can occur in one or several bones.

Diagnosis and Management of Paget's Disease

In 2018, a new patient-centred clinical Guideline was developed to provide recommendations for the diagnosis and management of Paget's Disease of Bone in adults. It provides direction to professionals, giving them a base on which to make decisions, and facilitates discussion with patients. Written by a group of experts in the field, the Guideline was prepared, on behalf of the Paget's Association, the European Calcified Tissue Society, and the International Osteoporosis Foundation. For details visit: **www.paget.org.uk**

Patient Information

Please ask your health professionals to complete this document, which has been developed for you to keep as a personal record of your health, in relation to Paget's disease. It should be taken with you to all health related appointments.

Excellence in Care and Research

This document was developed in conjunction with the Southampton Paget's Association Centre of Excellence: the Rheumatology Department of the University Hospital Southampton NHS Foundation Trust and the MRC Lifecourse Epidemiology Unit of the University of Southampton. This is one of a number of UK Centres of Excellence.

Information about the Paget's Association

The Paget's Association is the only UK charity to focus solely on Paget's Disease of Bone, funding research, raising awareness of the condition and providing high quality information and support for patients, carers and health professionals.



Name

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Date of birth

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NHS number

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GP

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Consultant

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Clinic/hospital

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Year of diagnosis

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Bone/s involved

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Consultant/GP signature

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Date

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Indicate which Bones are affected by Paget's Disease



X-rays

Date

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Findings

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Completed by (name)

..... Date.....

Date

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Findings

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Completed by (name)

..... Date.....

X-rays

Date

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Findings

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Completed by (name)

..... Date.....

Date

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Findings

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Completed by (name)

..... Date.....



Isotope Bone Scan

Yes/No

Date

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Findings

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Completed by (name)

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Date

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Isotope Bone Scan

Yes/No

Date

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Findings

.....
Completed by (name)

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Date

Blood Tests for Alkaline Phosphatase (ALP)

Date

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Result

Date

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Result

Date

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Result

Date

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Result

Date

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Result

Date

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Result

Date

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Result

Date

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Result

Date

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Result

Date

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Result

Relevant Blood Tests

Name of test

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Date

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Result

Name of test

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Date

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Result

Name of test

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Date

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Result

Name of test

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Date

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Result

Name of test

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Date

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Name of test

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Date

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Result

Relevant Blood Tests

Name of test

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Date

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Result

Name of test

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Date

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Result

Name of test

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Date

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Result

Name of test

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Date

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Result

Name of test

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Date

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Result

Name of test

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Date

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Result

Bisphosphonate Treatment

Yes/No

Date Drug

Completed by (name)

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Date

Date Drug

Completed by (name)

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Date

Date Drug

Completed by (name)

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Date

*The clinical Guideline (see page 2) recommends **zoledronic acid** as the first-line treatment for Paget's disease, in the UK.*



Fractures in Pagetic Bones

Details

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Date

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Completed by (name)

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Date

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Surgery in Paget's Disease

Prior to surgery, active disease can be brought under control with bisphosphonate treatment. This reduces vascularity, minimising the risk of excessive blood loss and reducing the chances of post-operative complications, such as loosening of a new joint.

In those who have Paget's disease, total knee and hip replacement for osteoarthritis is common and can be performed successfully in many, with good results.

Surgery Undertaken

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..... Date.....

Completed by (name)

..... Date.....



Surgery Undertaken

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..... Date.....

Completed by (name)

..... Date.....

Surgery Undertaken

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..... Date.....

Completed by (name)

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Medical History

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Medication List

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How to Contact the Paget's Association

General and Membership Enquires

Email **membership@paget.org.uk**

Telephone **0161 799 4646**

Nurse Helpline

Email **helpline@paget.org.uk**

Telephone **0161 799 4646**

Ask to speak to the Nurse

Membership

When you become a member of the Paget's Association, you join many others affected by Paget's disease. Membership provides support and information in various ways. All members receive a Paget's Information Pack and our quarterly Paget's Newsletter.



The Paget's Association

Registered Charity No. 266071

www.paget.org.uk

Tel: 0161 799 4646