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Title: The pleasure of play: playing with children when you have arthritis.

Article & version: Published version

Original citation & hyperlink:

Wade, M. , Cullen, L.A. and Barlow, J.H. (1998) The pleasure of play: playing with children when you have arthritis. *Disability, Pregnancy and Parenthood International*, volume 22 : 5-7.

<http://www.dppi.org.uk/journal/>

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Available in the CURVE Research Collection: February 2012

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The Pleasure of Play:

Playing with children when you have arthritis

The importance of play was a consistent theme to emerge from recent research carried out at the Psychosocial Rheumatology Research Centre of Coventry University, UK. Many parents and grandparents found that arthritis made it very difficult to play with their children and grandchildren. Although individual issues faced by parents depend on the type and severity of the condition, there are ways of making play easier, many of which are useful to all parents.

Play spans a wide range of activity with children of all ages, from birth to adolescence. It is vital, not only in developing the parent/child relationship, but also as an aid to learning and child development.

It is important to focus on the positive things you can do, to relax and enjoy the experience, letting your imagination and creativity flow. Time spent with children is invaluable, and there are many ways in which non-physical activities can be part of this experience. Reading with children is pleasurable and educational too. If holding a book is painful and difficult, try using a reading stand.

Talking and singing (if you enjoy that!) can be fun. If you don't like singing, then listening to music is an alternative. Combining this with a painting or drawing activity can be a relaxing and enjoyable way of spending time together.

Jill Holroyd, author of *Arthritis at your age?* provides a list of references to inspire the planning of non-physical activities. Many of these focus on learning through play. If you are tired, then tape recorded stories, children's videos, television programmes, computer games or interactive learning packages can be useful substitutes especially if you are able to cuddle your child or sit close by, providing comments and encouragement.

One parent advised always having something 'up your sleeve' to use on bad days, a special box of toys or something new that you can bring out if you are not feeling too good.

One parent shared with us her own experience of the times when she took a rest on the bed in the afternoons.

"The children used to come home from school and gather on the bed and talk and play. This became a very treasured part of the day".

The relationship is the important thing.

For young babies lying on their backs on the floor, a "baby gym" (a stand with various toys and play items hanging from it) can be stimulating, as can hanging mobiles and musical toys.

Most babies enjoy lying on activity mats, made of brightly coloured, padded cloth into which various soft toys, materials of differing textures and even sound devices are sewn. Musical play mats and themed (e.g. airport, farm, numbers, alphabet) mats are available from specialist nursery and disability suppliers.

Large activity 'rings' provide welcome and interesting places to put a baby for short periods of time. Just sitting a baby in a first stage car seat on a safe surface of a suitable height where you can interact is entertaining for the child. One mother adapted such a seat, fitting it onto a wheeled "tea-trolley" which she could move around the house with her.

Playing with a baby doesn't mean always getting down onto the floor. Adapt a bed, cot or table top into a 'play area' for the baby. Then you can play at a height to suit you. Make sure the baby is prevented from falling off. If you are improvising, avoid fixings like wing nuts that can be twiddled off and swallowed.

Lying or sitting on the floor has the advantages of allowing babies and toddlers to use parents as a climbing frame and can be great fun for all concerned. It may be hard to sit for extended lengths of time. One parent advised:

"Be disciplined, play for so long, then move about, then play again."

Getting onto the floor can be difficult. One suggestion is to find a suitable height adjustable office chair, which can be lowered to within 30cm of the ground, thus making it easier to get down to the child's view of the world. Always ensure that you will be able to get back up again afterwards.

Another idea is to use a bath lift, traditionally used for lowering someone into the bath, as a means of lowering yourself down onto the floor to play. Strategically placed hand-rails fixed to the wall might help. A stool with wheels, or a car mechanic's 'roller board' may be useful for moving around, once down.

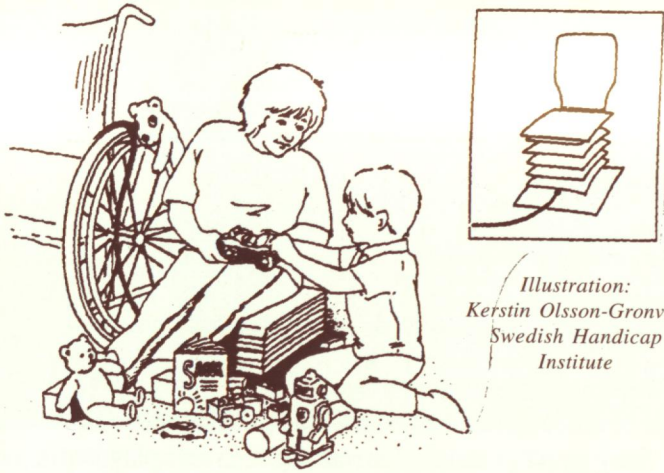


Illustration:
Kerstin Olsson-Gronvik,
Swedish Handicap
Institute

Wherever you are playing, your posture is important. If you are spending quite a lot of time on the floor it is important to think about posture and support. It may be possible to prop yourself up against a settee, chair or wall during play. One parent used a salvaged front seat from a car to sit on, as it was very low, comfortable and gave her good support.

Once babies are sitting, they can be placed in highchair or booster seats, where they can play using the tray or a table, at a suitable height for the parent. 'Static baby walkers' or 'entertainer seats' are safe, interesting places for babies to sit for short periods of time.

Some parents have invested in play tables designed for use in nursery or school settings. Although not cheap, they allow children to play at a height to suit themselves and a seated adult. Some of them have troughs in the top for sand or water, and an optional flat cover. A sturdy coffee table can be a good height to double as a play table.

Playpens can be useful, but many parents with arthritis find them difficult to use because of the need to lift the child in and out. They can be adapted to allow one side to open as a 'gate-side' or have the base raised to a more suitable height for the parent.

Some parents find it useful to think of one room in the house as a 'safe room', or a 'playroom' with a suitable safety gate in the doorway. Ideally, this should be a room where you, the parent, will spend a good deal of time, and once safe, can relax in it with your child.

Put a lot of thought into making the room a safe environment where you and your child can play. Alternatively, a play corner could be set up, if space allows. This helps to contain toys in a designated play area, making them accessible to the child and at the same time creating a safer environment for everyone to move around. Foam wedges, shapes or panels can be fitted together with Velcro strips if a boundary edge is thought necessary and if finances allow. Put up a 'white board', black board or even large pages of recycled computer paper for a child to draw on.

Picking up toys and storing them is every parent's nightmare. One idea to reduce the amount of work is to

make tidying up into a game (Mary Poppins style), involving as many children as possible. Games can be themed, picking up toys according to colour or within a defined time. Children usually love a challenge. Reduce the number of times you need to pick up after a young baby by attaching toys and bottle to clips that are in turn attached to the buggy or highchair. Clips are available, although they may need adaptation. Try using a long-handled dustpan and brush or 'easy-reacher' to collect things off the floor.

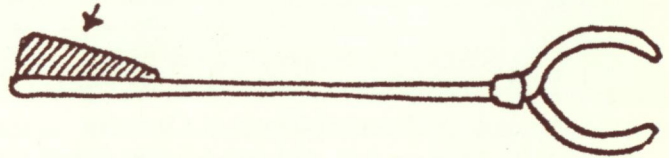


Illustration: Anne Kondrup, Ergotherapist, Danish Rheumatism

Storage of toys is another consideration. A cart or trolley box on wheels can be useful as a child can move it around independently and possibly use it for support when walking. If you find bending to the bottom of toy boxes difficult, raise them.



Illustration:
Anne Kondrup,
Ergotherapist, Danish
Rheumatism Associa-
tion

Creativity when choosing toys can make play easier, for example a ball on a string, or tricycle with a long push handle can be useful. Local Toy Libraries are a goldmine of ideas and provide support for parents as well as lending toys. **Play Matters** is the campaign name for the joint venture between the National Association of Toy and Leisure Libraries and ACTIVE. The first of these organisations publishes **The Annual Good Toy Guide** based on their research and a range of booklets, with advice on various aspects of play for the developing child. The second organisation, ACTIVE, encourages the development of play and leisure equipment for individual children and adults with disabilities.

Swimming can be therapeutic for parents, as well as fun for both parent and child. Many places have baby and toddler swimming pools which are very good because the water is generally warmer than in the full size pool and this can ease stiff, painful joints while you play with your child. It may be helpful to take a friend, family member, assistant or local volunteer along to assist with carrying, dressing and undressing. Several

brands of baby floats or swim aids are available in nursery and sports shops. These allow a young baby or toddler to bob along beside a watchful parent.

One father with arthritis said:

"I enjoy taking them swimming. I know it won't be too physically demanding, as children will generally play happily together in the water for long periods of time. Although the duration of the whole outing may be long, the duration of physical exertion is lessened."



Children like any kind of water play. This could be a bowl of water in the garden (set on a low table or bench, bringing it to a good height for the parent too), helping wash up in the kitchen sink, water-pistols outdoors in the summer, or simply bath-time. As one mother put it:

"I really enjoy bath play with my son. We both sit in the bath, relaxing and playing, splashing and talking together. It's an excellent way of having 'time out'."

If you feel your child would benefit from more active, physical play, some restaurants, shops and leisure centres have play areas attached. You don't always have to eat at the restaurant for your children to use the facility. For a small fee, your children can enjoy ball pools and fun activities while you watch.

Outdoors, parents may experience difficulties keeping up with children. Try a wrist strap or child's reins to keep your child close. Carabina clips from camping and sailing shops can be helpful for fastening harnesses on buggies and reins. It may help to go out with a group of friends. Choose safe, traffic free and possibly enclosed areas, to increase peace of mind. It is useful to develop the use of your voice as a tool, to advise and encourage them to participate independently in activities. Set boundaries with the children.

It may be helpful to be referred to an occupational therapist or physiotherapist if you are experiencing difficulties. Alternatively it may help to join local, national or international support groups where you can exchange ideas with people in similar situations.

**Mary Wade, Lesley Cullen, Dr Nadine Foster,
Professor Julie Barlow.**

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- National Association of Toy and Leisure Libraries (Play Matters), 68 Churchway, London, NW1 1LT, UK. Tel: 0171 387 9592.
- Ostensen M & Rugelsjoen A (1994). "Being a Rheumatic Mother". Haraldus Medical Communications, Trondheim, Norway.
- Parker M & Sandberg K (1995), "Smarbarnsforaldrar Med Rorelsehinder", Handikappinstituttet, Vallingby, (a Swedish publication).

Suppliers:

- Smith and Nephew Homecraft Ltd., Sidings Road, Lowmoor Road Industrial Estate, Kirby-in-Ashfield, Nottinghamshire NG17 7JZ.
Tel: 01623 722 337 Fax: 01623 752 022
- Nottingham Rehab, Ludlow Road, West Bridgeford, Nottingham NG2 6HD.
Tel: 0115 9360 322 Fax: 0115 9452 124

Other useful contacts:

- Arthritis Care and Young Arthritis Care,
18 Stephenson Way, London, NW1 2HD, UK.
Tel: 0171 916 1500
- ParentAbility (A National Childbirth Trust Network for Disabled Parents), Alexandra House, Oldham Terrace, Acton, London, W3 6NH, UK.
Tel: 0181 992 8637.
- Website of the "Center for Mothers with Rheumatic Disease", Trondheim, Norway, providing a list of articles published by researchers at this centre. <http://www.forum.no/rheuma/literature.htm>

Examples of products shown here are for ideas and do not imply **DPPi** endorsement of those products.

Cover photograph is courtesy of Rupert Langham, who is pictured playing with his son, Jack.

Action for ME

Kerry Tolley is planning to hold a seminar on Myalgic Encephalomyelitis in pregnancy for midwives. She would like to hear from midwives who would like to attend and also from organisations that may be able to assist in running the event in some way. Please contact

Kerry Tolley

Action for ME

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