

Living well
WITH ARTHRITIS



PUTTING PEOPLE WITH ARTHRITIS AND OSTEOPOROSIS AT THE CENTRE OF WHAT WE DO

Arthritis Support Groups

A guide to setting up and
maintaining a group



Arthritis & Osteoporosis Tasmania is a not-for-profit, non-government incorporated organisation, that provides information and support free of charge of people affected by arthritis, osteoporosis and related musculoskeletal conditions throughout Tasmania. These services are made possible through the generous donations of Tasmanians and we thank them for their continued support. If you would like to know more about the information and support services provided by Arthritis & Osteoporosis Tasmania, call our Helpline 1800 011 041 (toll free).



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WHAT IS A SUPPORT GROUP?



Support groups are a way for people with arthritis, or who have experienced arthritis in their families, to come together and provide emotional and moral support for one another.

People with arthritis can:

- share experiences and emotions in a safe environment
- feel understood
- know they are not alone
- give and receive support from people facing the same challenges
- exchange advice and practical tips about living with arthritis
- find new ways to solve problems
- create friendships and reduce feelings of isolation
- learn about and practice self management.

Types of support groups

There are many different types of support groups, including ones that:

- cater for all types of arthritis
- focus on a particular condition
- are led by health professionals
- are organised and run by people with arthritis
- meet face-to-face
- provide support via the internet, such as using Facebook or online forums.

Limitations of a support group

The purpose of a support group is not to provide complex medical information or recommendations for arthritis treatments. Members wanting specific information about their condition or treatment options can be encouraged to contact their doctor, rheumatologist, other health care professional or Arthritis & Osteoporosis Tasmania.

Many people joining a support group are looking for a friendly, informal source of reassurance and hope. However, if people are experiencing great emotional distress or have very complex problems, they may need more support and counselling that the group can offer. Contact Arthritis & Osteoporosis Tasmania for more advice and information about support services available for people in need.

About Arthritis & Osteoporosis Tasmania

Arthritis & Osteoporosis Tasmania is a not-for-profit incorporated organisation, established in 1976 to make a positive difference to the lives of people affected by arthritis, osteoporosis and related conditions.

Governed by a Board of Directors, Arthritis & Osteoporosis Tasmania is supported by rheumatologists, allied health professionals, two full time and two part time staff members, and a large team of volunteers.

At Arthritis & Osteoporosis Tasmania we understand the serious impact that arthritis, osteoporosis and related conditions can have and offer our services with compassion and respect for each person's unique experience and situation.

1 in **4**
Tasmanians
suffer from arthritis



How can Arthritis & Osteoporosis Tasmania support your group?

Arthritis & Osteoporosis Tasmania can act as a resource for your support group in many ways, including:

- providing education sessions about arthritis and osteoporosis, particularly when the group is first starting
- keeping the group up-to-date with information about arthritis
- assisting your group to find free/low cost meeting rooms and ideas for guest speakers
- helping you to resolve problems with members or other issues
- advertising your group and upcoming meetings.

Gather help

Starting a new support group involves many tasks so think about how you can best share the workload from the outset. The most successful, longest-running groups tend to be ones where the work is shared between members, rather than being the full responsibility of just one person. Try to find three to four people to help get the group started. These may be people you already know, or you may need to spread the word by posting flyers around your local area, or asking family, friends and Arthritis & Osteoporosis Tasmania for suggestions of interested people.

Decide how to manage the group

Think about how best to share the work involved in running the group and making decisions. Some groups may prefer to be more informal, with different people taking on various jobs as they come up. Other groups might prefer to divide up roles and responsibilities, for example nominating a facilitator. This person might act as the key contact person for the group, liaise with Arthritis & Osteoporosis Tasmania and other organisations, and generally oversees the running of the group. There is no right or wrong way to set up a support group so pick a structure that works best for your group.

STARTING A SUPPORT GROUP

If you or a loved one has arthritis you may be interested in starting an arthritis support group to meet other people facing the same difficulties. This can be a very rewarding process but it does require a lot of commitment.

Here are some steps you could follow when establishing a new group:



Decide who will run the meetings

The group will need to choose someone to run the support group meetings. Some groups elect to have their facilitator run the support group meetings, while other groups may appoint a different person, or people, to help share the load. Alternatively, some groups may encourage all members to take a turn in running the meeting. This person will have a large role to play in setting the tone of the meeting so try to choose a good communicator who is skilled at handling different types of personalities within a group.

Plan your group

From the outset, your group will need to make decisions regarding the type of group you are creating. Consider the following:

Who can join your group?

- People with any type of arthritis or just a specific type of arthritis?
- Men, women or both?
- Can carers or support people join?
- Any specific age, language or ethnic group?

When can people join?

- Will your group accept new members at any stage or is it restricted to a certain number of people who join at the beginning?

What is the purpose of the group?

- To foster emotional support between members (ie. group focuses on sharing members' experiences/feelings and building friendships between people through social get togethers)? and/or
- Provide information (eg. through guest speakers and educational sessions)? and/or
- Raise funds (eg. fundraising activities for Arthritis & Osteoporosis Tasmania)?

Plan meetings

When scheduling group meetings, consider the following:

- Time of day – are your potential members likely to work so may prefer evening meetings, or would daytime meetings be more suitable?
- Day of the week – weekdays are usually easier than weekends for recruiting speakers and participants.
- Frequency – monthly, fortnightly or weekly? Consider whether your group will continue to run over school holidays.
- Duration of meeting
- Scheduling the first meeting – give yourself enough time, at least four to six weeks, to publicise the first meeting throughout the community.
- Venue – try to find somewhere that:
 - is free or low cost
 - has ample parking or is easily accessed by public transport
 - is accessible to people with disabilities
 - has tea/coffee facilities
 - can be reserved for all your meetings over the next year
 - has toilets nearby
 - has comfortable furniture that can be easily rearranged.
 - Possible meeting rooms can be found in community health centres, community centres, town halls, libraries, church halls and local clubs.

Recruit group members

Think about where people are most likely to hear about your group:

- Flyers posted at community health centres, shopping centres, medical clinics, pharmacies, local churches and libraries
- Announcements on community radio stations
- Local newspapers.

Make sure you include details of the group's name, membership eligibility, meeting place/date/time and a key contact person.

Practical issues

There are several other practical issues to consider as you are starting out:

- **Mailing address**
Your group will need a mailing address for correspondence. You may choose to use someone's home address or hire a post office box, or ask Arthritis & Osteoporosis Tasmania whether it's possible to direct your mail to their address.
- **Bank accounts**
If your group plans on receiving and spending money, you may need to set up a bank account in the group's name. However, most groups only require a small amount of funds to function effectively, taking advantage of free meeting places and providing tea/coffee for a small donation from group members.
- **Insurance**
Contact Arthritis & Osteoporosis Tasmania for details on the type of insurance cover provided to arthritis support groups.
- **Business/legal issues**
Most support groups do not require an Australian Business Number (ABN), to register for GST or register as a deductible gift recipient.

For further advice on any of the above issues talk to your accountant or Arthritis & Osteoporosis Tasmania.



The goal of the first meeting is to make people feel welcome so they will want to come back.

The first meeting

The goal of the first meeting is to make people feel welcome so they will want to come back. Here are some tips to help your first meeting run smoothly:

BEFORE THE FIRST MEETING

- Write an agenda (a list of items/topics to cover during the meeting).
- Have an attendance book to record names, phone numbers, addresses and email addresses.
- Bring pens and name tags.
- Clearly mark the room where the meeting is being held – you may even wish to put up signs directing people to the room.
- Arrange chairs so everyone is comfortable, perhaps in a circle to facilitate group discussion.
- Have refreshments, tea, coffee, sugar, milk, cups, spoons and napkins readily available.

DURING THE MEETING

- Ensure you have someone to warmly greet people at the door.
- Ask them to fill out their details in the attendance book and give them a name tag (ensure facilitators and committee members are also wearing name tags).
- After a brief welcome, include time for a discussion of the purpose of the group and introduce a few ground rules, including confidentiality.
- Allow time for everyone to briefly introduce themselves to the group and answer a question such as 'what is one thing you'd like to see come out of this group?' or 'what is something positive you did this week?'
- Finish on time – allow time for socialising or an informal chat at the end of the meeting if possible.
- Confirm time and date of the next meeting (you may even like to have the details printed on a flyer for people to take with them as reminder).

KEEPING THE SUPPORT GROUP GOING

Plan ahead

Good organisation and planning is the key to maintaining a support group. Plan meetings several months ahead of time, rather than just working on a month-to-month basis. This will give the group enough time to book speakers and organise other activities or resources, such as flyers/notices. Wherever possible, include the members of the group in planning and organising meetings, activities and other tasks. This will help foster the sense that the group is run by the group, for the group.

Running efficient meetings

Here are some tips for the smooth running of a meeting:

- Consider planning an agenda before the meeting. Hand a copy of the agenda to attendees as they arrive so they know what to expect from the meeting.
- Start on time.
- Welcome everyone to the meeting, particularly new members.
- Let people know it's fine to get up regularly and stretch. Possibly include a short stretch break in the meeting if time permits.
- Welcome the guest speaker, if relevant.
- Outline the agenda and what will be covered during the meeting.
- Thank the guest speaker for their presentation.
- Finish on time. Remind people of the date and time of the next meeting.
- If possible, encourage people to stay behind for refreshments and a chat.



Group rules

The group may consider developing agreements, or rules, for members to follow. This can help create a positive group environment, and minimise conflict during meetings. These ground rules can be given to members as they join, and reinforced to the group at times throughout the year.

Some examples of group agreements include:

- Minimise distractions – turn off or silence electronic devices.
- Be respectful of others and their ideas. Do not talk over or interrupt others. Be sure the person speaking has finished before commenting.
- Accept members just as they are and avoid making judgements.
- Give full attention to the person speaking and avoid having side conversations.
- Maintain confidentiality – whatever is said in the group stays in the group.
- Encourage participation. Support groups are most beneficial when all participants have the opportunity to share and discuss issues. Notice silent people in the group and encourage them to contribute. Be mindful of the limited time and try to ensure each person has enough time to speak if they wish.
- Focus on the positive. Allow members to express negative or angry feelings but try to focus on recent successes and new opportunities.
- The support group is not to be used as a forum to promote particular products or treatments. Appreciate that what works for one person may not work for another, and accept that people may have very different perspectives and approaches to the management of their arthritis.



Guest speakers can come from a wide variety of backgrounds and do not necessarily need to be limited to arthritis specialists.

Guest speakers

Depending on the group, guest speakers may be useful inclusions. Guest speakers can come from a wide variety of backgrounds and do not necessarily need to be limited to arthritis specialists. Speakers could range from health professionals (eg. physiotherapist, podiatrist) to local identities or other community organisations/groups. Don't forget to ask your members for ideas of guest speakers.

When contacting potential speakers, try to have the following information available:

- time allocated for their presentation, including time for questions
- what time they need to arrive, and whether you would like them to stay for the remainder of the meeting
- the general characteristics of your group – gender, age, number of attendees
- the kinds of topics your members would like them to cover during their presentation
- equipment available – for example whiteboard and pens, laptop and data projector.

It is a good idea to call the speaker a week or two before the meeting to confirm their attendance.

Member feedback

It is important to talk to your members about whether the group is continuing to meet their needs, or whether the group should change anything in the way it runs. You could informally ask people face-to-face, or put together a short survey every year to ask for members' input.

Ongoing promotion

Continuing to promote the group throughout the community is important for attracting new members. Ask members for ideas they may have, as well as:

- leaving flyers at the local hospital, community health centre, medical clinics, pharmacies, local churches, community centres, libraries and other public noticeboards.
- contacting the local paper about getting a short feature or article about the group in the paper. You may have a member of the group who is willing to be interviewed and would make an interesting and inspiring story for others to read.
- contacting local community radio stations about including information about meetings in community announcements.
- including the group's details in local government directories listing community groups and events.

Continuing to promote the group throughout the community is important for attracting new members.

Potential pitfalls

LOW ATTENDANCE

Look for the source of the problem, by talking to a few members or surveying the group. Potential causes include:

- Unpopular speaker/topic
- Time of the year, for example school holidays, winter, weather.
- Timing of the meetings
- Meeting location, for example difficulty with parking or using public transport.
- People no longer need the support group.

The group may choose to continue on with smaller numbers, make a few changes and try harder to recruit new people, or fold the group.

LEADER BURNOUT

- Consider having two facilitators to support each other.
- Ensure members are involved in running the support group. Share the tasks as widely as you can, identify potential leaders and have regular opportunities for a change of leadership. Groups that have as many members as possible involved in the running, planning and organisation of the group tend to be more successful.

TIPS FOR FACILITATORS

What is the role of the facilitator?

Facilitators play an essential role in creating a successful group. A good facilitator can:

- create a safe, friendly and welcoming environment to encourage discussion and sharing emotions
- stimulate balanced discussion by respecting the views of others and encouraging everyone to participate
- be an active listener and allow people to tell their story without giving advice or counselling
- keep the discussion focused and ensure the meeting runs to time
- maintain confidentiality
- follow up on questions from meetings. You don't need to always have the answer but it is useful to know who you can refer to or where to go for more information.
- be sincere, genuine and good-humoured.

Handling difficult situations

All groups will have times when problems arise during meetings and a facilitator needs to have some tools to deal with these commonly experienced issues. Try some of the tips listed below or contact Arthritis & Osteoporosis Tasmania for further advice or intervention:

PROBLEM	SOLUTIONS
A person is not involving themselves in discussions	<ul style="list-style-type: none">• Break into smaller groups or pairs during discussion• Have a comments/suggestions box for members to share their ideas in writing• Have a discrete chat with the participant, either before or after a meeting, to find out whether they are happy with their participation or if they would like to contribute more.
A person is dominating the discussion or being disruptive	<ul style="list-style-type: none">• Hold the meeting in a circle and move around the group, giving each person a turn to talk.• Divide the group into pairs to share ideas.• Actively involve others during the discussion.• A time limit can be imposed on speakers if necessary.• Go back to the group agreement if necessary to remind everyone of acceptable group behaviour.• Talk to the person in private. Acknowledge their valuable contribution but gently remind them that everyone in the group needs to have a chance to contribute. Encourage them to wait until others have spoken before putting their views forward



Group negativity

- Refocus the discussion onto positive aspects – try asking for recent achievements or successes.
 - Allow people to share their difficulties but then encourage the group to share solutions for the problem.
-

Members of the group spreading misinformation or promoting particular products or treatments

- Acknowledge their experience but reinforce to the group that many treatments or products on the market, particularly complementary therapies, are not well proven (both in terms of effectiveness as well as risks/side effects).
 - Have a discussion to reinforce that what works for one person may not necessarily work for another.
 - Discreetly talk to the person about how to talk positively about their experiences with a particular treatment, without trying to force others to try it.
-

Personality clash with a member of the group

- If you have a co-facilitator, ask them to help you deal with the person.
 - Have someone to debrief with after the meeting – perhaps a fellow group member or maybe a friend or family member not involved in the group. Be mindful of confidentiality.
-

Disagreements between members

- Talk to the people involved and try to encourage people to see both sides of the story.
 - If possible, arrange a time for the members to meet and discuss their concerns with each other. If you feel you need additional support, contact Arthritis & Osteoporosis Tasmania for advice.
-

Catering for members with disabilities

- Rearrange furniture to make room for equipment such as wheelchairs, electric scooters or walking frames.
 - Ask the person what help they need during the meeting, such as opening the door to go to the bathroom, or carrying their cup of tea back to their seat.
-

Catering for non-English speaking members

- Suggest that a family member, friend or translator accompany them to the meeting. They can quietly explain what is happening and translate any of their comments back to the group.
 - Encourage them to contact Arthritis & Osteoporosis Tasmania for the various information sheets available in languages other than English.
-

RESOURCES AND FURTHER INFORMATION

Arthritis Helpline

The Arthritis Helpline 1800 011 041 provides information, education and support for people with arthritis. Staffed by trained volunteers this service provides information and support in relation to arthritis, osteoporosis and related musculoskeletal conditions. The Arthritis Helpline can also provide a range of educational resources about the various types of arthritis and treatment strategies, including healthy lifestyle and self-management options.

Websites

- Arthritis & Osteoporosis Tasmania www.arthritistas.org.au
- Arthritis Australia www.arthritisaustralia.com.au
- My Joint Pain www.myjointpain.org.au
- Self Help Queensland www.selfhelpqld.org.au



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Arthritis Helpline
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DECLARATION OF PRIVACY

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