



LYMPHOEDEMA ACTION ALLIANCE – MEMORANDUM OF UNDERSTANDING

Background

Lymphoedema is a chronic and progressive condition that afflicts an estimated 300,000 people in Australia, affecting their quality of life, health, work and relationships, especially when not appropriately treated. Lymphoedema suffers from lack of funding, and awareness within medical professions and the wider community. The condition is not well diagnosed, and many patients, especially those with non-cancer related lymphoedema, struggle to access services and treatment. Access to treatment and compression garments is particularly problematic for people who cannot afford to pay privately. In addition there is a gap in service provision between patients living in metropolitan areas, and those in rural and regional areas.

In October 2013, and again February 2014, representatives of key lymphoedema stakeholder organisations met together to discuss possible collaborative advocacy on lymphoedema issues, and identify issues for collective action. The group also explored interest in forming an Alliance to progress this work.

Alliance goals

The Alliance will work to reduce the unnecessary suffering of people who have lymphoedema, by ensuring timely access to affordable lymphoedema services, regardless of where people live, their financial status and their health situation.

The specific advocacy objectives of the Alliance are:

1. Equitable access to quality lymphoedema services in NSW (NSW specific issue)
2. Equitable and sustainable access to lymphoedema compression garments for patients with lymphoedema in Australia (national issue).

To achieve these objectives, the Alliance will:

- a) Plan, execute and evaluate advocacy strategies designed to persuade relevant decision makers above mentioned advocacy objectives (namely implementation of best practice clinical guidelines as government policy, and inclusion of compression garments in an equitable and sustainable access scheme).
- b) Raise public awareness about and support for the goals and objectives of the Lymphoedema Action Alliance.
- c) Engage other potential partners in the work of the Alliance.

The advocacy strategies for objectives 1 and 2 are outlined in a separate document and form part of this MOU.

Principles

Key principles in relation to the operation of the alliance and its joint advocacy include:

1. The Alliance represents a shared interest and commitment to particular policy changes that would assist people with lymphoedema. Therefore all Alliance members must endorse the specific advocacy objectives outlined above
2. While member organisations might individually continue to pursue additional objectives in relation to addressing the needs of people with lymphoedema, Alliance members cannot hold policy positions or undertake advocacy that is contrary to or in conflict with the advocacy objectives of the Alliance
3. Advocacy activities will be conducted in a manner that promotes the good standing and reputation of member organisations, and is seen to be fair and reasonable under the circumstances
4. The advocacy strategies will be based on a model of seeking to inform, influence and persuade decision makers to achieve the objectives, and will only move to escalated tactics when other approaches have been exhausted. This determination will be made by the steering committee, in consultation with Alliance members.

Alliance structure

The Alliance shall be made up of organisations with an interest in the goals outlined in this MOU.

A Steering Committee will be established for the Alliance. The Steering Committee should provide a balance of interests across primary and secondary lymphoedema, and across state and national representation.

The Steering Committee is responsible for determining advocacy tactics and actions, consistent with the agreed strategy and will guide all stages of the development, activities and evaluation of the Alliance.

There will be two working groups established – one to work on the state issue and one on the national issue. Each working group will select a facilitator from within its membership who will be responsible for leading the work of the working group. The facilitator from each working group will become a member of the Steering Committee.

The Alliance can consult with and seek advice from individual specialist and consultants who may also join working groups.

Members of the Alliance can choose to withdraw from the Alliance at any time. Organisations and individuals can seek to join the Alliance at any time.

While the Alliance is made up of members, the Alliance will always be presented as a collective entity, as will its positions and statements.

Membership

Membership is open to organisations that:

1. Endorse and support the advocacy objectives outlined
2. Commit to supporting the advocacy strategy to achieve the objectives
3. Agree to consider each activity in support of the advocacy strategy and participate as appropriate to their means and resources.

Member organisations are to nominate at least one representative to either or both working groups, and a proxy (back-up representative) for each working group they are part of. Representatives of an organisation will act as the liaison person for the Alliance for their own organisation, and will oversee their organisation's implementation of the advocacy strategies. The nominated representatives should be able to act with the authority of their organisation in contributing to Alliance decisions and committing their organisation resources to the work of the Alliance.

Expectations of Alliance members

Each Alliance member and representative will:

- Work in accordance with this MOU
- Contribute as agreed to the strategy for our shared advocacy objectives
- Consent to having their name used in association with the Alliance and all its outputs, including media releases from the Alliance
- Review and approve all draft media statements within 48 hours
- Distribute information and calls to action amongst their membership and networks
- Use their networks, relationships and resources to further the objectives of the Alliance, in a manner consistent with the advocacy strategy
- Adopt the advocacy objectives outlined in this MOU as formal policy position of their organisation
- Inform the Alliance of advocacy activities undertake in support of our shared objectives.

Confidentiality

Members of the Alliance agree to respect the confidentiality of material presented to, and produced by, the Alliance, and to not distribute it to a wider audience without permission.

Media and other public representation

The Alliance (through the Steering Committee) will nominate spokespeople for the purposes of media, political engagement or other public representation.

Any media comment or discussions with politicians or public servants conducted under the name of the Alliance must be consistent with the Alliance's agreed public message and position.

Where members are making comments on lymphoedema issues as individual organisations or that relate to issues beyond our shared objectives, care should be taken to distinguish these comments from those of the Alliance.

Operation of the Alliance

The Steering Committee will be chaired by a nominee of the Committee.

The Steering Committee will update the advocacy strategy and plans for the Alliance on a six-monthly basis. Members of the Alliance will receive updates at least every 6 months, and be consulted about the overall advocacy strategy and plan.

Alliance members will contribute by:

- providing at least one representative for at least one working group;
- participating in the activities designed to achieve our shared advocacy objectives
- using their own networks and positions to promote the advocacy objectives of the Alliance

Cancer Council NSW will provide the following to assist in the work of the Alliance:

- Secretariat and meeting support and co-ordination for the Steering Committee. This includes setting up meetings, venue and catering, setting of agenda and record keeping
- Covering the cost of teleconferences of the Steering Committee
- Facilitating planning workshops
- Support in developing position statements, briefing papers and other documents.

Communications with Alliance members will primarily be conducted by email as well as face-to-face and teleconference meetings. The working groups are expected to meet primarily face-to-face and by teleconference.

The Alliance and its activities will be reviewed in 12 months to assess its effectiveness in achieving its objectives and in its operation.