The Next 5 Years
Mesothelioma UK 2016-2021 Strategy

Dedicated to Making Mesothelioma Matter
Introduction

The Mesothelioma UK National Resource Centre was launched in 2004 with financial support, initially from Macmillan Cancer Support and later from industry colleagues, The Mick Knighton Mesothelioma Research Fund and generous private donations.

To secure the Centre’s long term future, the Mesothelioma UK Charitable Trust was established in 2009 and the new charity immediately became fully responsible for securing sufficient income to support the resource centres activities.

The financial independence of becoming a charity meant Mesothelioma UK has been able to continually grow and develop. Through integrated working practices the charity now significantly compliments and supports UK health care providers to meet the needs of people living with Mesothelioma, particularly with regard to the provision of specialist nursing posts in the UK.

This is Mesothelioma UK’s first Strategy Document. Thank you for taking the time to read it, and please do send your comments to the team.

Liz Darlison
Director of Services
September 2016
Mesothelioma UK is hosted by the University Hospitals of Leicester NHS Trust; the operational team are based at the Glenfield Hospital site. The Clinical Nurse Specialists are based in NHS hospitals across the UK.

**Operational Team**

- **Director of Services**: Liz Darlison
- **Business Manager**: Ghislaine Boyd
- **Fundraising Manager**: Jill Lemon
- **Finance Officer**: Tracey Calvert
- **Fundraising Officer**: Vacant
- **Helpline Co-ordinator & PA**: Debbie Neale
- **Benefits Advisor**: Caroline Barry
- **Admin Assistant**: Rubina Sheikh
- **Office Apprentice**: Bruschelle Noronha
- **Website Co-ordinator**: Mita Navekar
- **Communications Team**: Sandstar Communications

Dock 006, 75 Exploration Drive, Leicester LE4 5NU

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Clinical Nurse Specialists

Members of Mesothelioma UK Nurse Specialist Team
Liz Darlison, Lorraine Creech, Helena Stanley, Leah Taylor, Hannah Ball, Anne Moylan.

Lead Consultant Nurse
Liz Darlison, Leicester

Clinical Nurse Specialist Team Leaders
Lorraine Creech, Manchester
Anne Moylan, Portsmouth

Clinical Nurse Specialists
Hannah Ball, Oxford
Simon Bolton, Yorkshire
Jan Devlin, Glasgow
Christine Jones, Plymouth
Karen Lord, Leicester
Kate Slaven, Cambridge
Leah Taylor, North East
Helena Stanley, Sheffield
TBC, London
TBC, Wales
TBC, Manchester

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Board of Trustees

Alida Coates
Ruth Davies
David Hetmanski
Dawn McKinley
Professor Mick Peake (chair)

Advisory Board

Mesothelioma UK convenes two meetings a year of the charity’s advisory board.

The Mesothelioma Advisory Board is an expert advisory group who come together to discuss and make recommendations concerning the needs of Mesothelioma sufferers. They review and comment on any relevant policies, service specifications and generally advise and support the charity’s trustees, nursing and operational team.

Members consist of patients, carers, health care professionals and industry representatives.

Dr Jeremy Steele is the Chair.

Ambassadors

A number of Mesothelioma UK supporters are approved ambassadors for Mesothelioma UK. Ambassadors promote Mesothelioma UK and represent the charity across the UK – particularly at functions and events where it is not possible for one of the operational team of nurse specialists to attend.
Currently, Mesothelioma UK:

- Provides funding for 11 Mesothelioma Nurse Specialists based in NHS hospital trusts across the UK (+ 3 vacancies)
- Funds a Citizens Advice Bureau specialist Mesothelioma benefits advisor
- Provides funding for research dedicated to Mesothelioma (£175k in 2015)
- Provides a range of Mesothelioma Information which is Information Standard accredited
- Provides a Freephone helpline with access to specialist Mesothelioma nurses
- Collates UK clinical trial availability and promotes equitable access
- Maintains a comprehensive website
- Produces and distributes a quarterly newsletter
- Holds regular conferences and educational events for patients, carers and health care professionals
- Delivers an accredited course in Mesothelioma (in partnership with The Royal Marsden School)
- Campaigns to raise awareness about the dangers of asbestos
- Achieve sufficient income to meet annual operational costs

Our Vision...

- To be a ‘Mesothelioma Essential One Stop Shop’ for up to date Mesothelioma support, information and education.
- Support the NHS to drive up standards and ensure equitable access to world class treatment, trials and care.
- To help the UK to lead the way in making Mesothelioma history through world class audit, research and clinical trials.
- To raise the profile of Mesothelioma to help prevent future cases of asbestos related disease.
Our 5 Year Strategy:

The current situation

- The UK has the highest incidence of Mesothelioma in the world.
- The incidence continues to rise.
- National Audit shows that we are making improvements in survival and breakthroughs in basic science suggest more could be achieved.
- There is an unacceptable variation in access to specialist treatment, care and clinical trials.
- The range of anti-cancer targets and treatments is growing rapidly.
- Mesothelioma UK is an established, growing and well respected charity that is central to UK and global Mesothelioma community.
- Mesothelioma UK has successfully introduced a ‘Hub and Spoke’ approach to providing Mesothelioma CNC’s across the UK.
- The NHS has the infrastructure and the health care experts to provide world class standards across the whole patient care pathway.

Purpose

- Outline a 5 year strategic plan that reflects Mesothelioma UK’s vision.
- State the key priorities for the Mesothelioma UK team (Trustees, Operational Team and Clinical Nurse Specialists) to work toward.
- Provide supporters and sponsors with a clear insight into Mesothelioma UK’s priorities for the next 5 years.
- To be adaptable to reflect changing need.
Structure

The Mesothelioma UK Strategy will follow 5 work streams:

1 Finance and Fundraising
2 Driving up Standards and Equitable Access
3 Support, Information and Education
4 Research, Audit and Evaluation
5 Prevention and Awareness

1 Finance and Fundraising

To increase Mesothelioma UK income from £0.5 to £3 million per year by 2021.

HOW:

a) Expand Fundraising Team
b) Increase individual fundraisers activity by 25%
c) Develop legacy income stream
d) Source income from appropriate grants and trusts
e) Increase corporate (Pharma, Legal and related companies) sponsorship
f) Establish targeted fundraising campaigns (eg: regionally or Sport4Meso)
g) Increase communication and marketing activity related to income generation

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2 Driving up Standards and Equitable Access

Support the NHS to drive up standards and ensure equitable access to world class treatment, trials and care.

HOW:

a) Increase the number of CNS’s supported by Mesothelioma UK to 28
b) Support the establishing of a National Peritoneal Mesothelioma Service
c) Support the establishing of Mesothelioma Multi-disciplinary Teams
d) Improve access to Clinical Trial information
e) Improve Mesothelioma UK contacts register
f) Support the establishing of a National Mesothelioma Coalition
g) Develop Decision support tools for clinical practice
h) Provide Service Specification/optimal pathway/commissioning advice
i) Establish a Peer Review service
j) Work with Global Partners to explore international need for virtual network

3 Support, Information and Education

The charity to be recognised as a ‘Mesothelioma Essential One Stop Shop’ providing up to date support, information and education.

HOW:

a) Increase Mesothelioma UK Information Catalogue
b) Increase Website and social networking activity by 50%
c) Evaluate and review newsletter content and distribution
d) Increase publication and presentations delivered by clinical team
e) Forge strong links with Cancer Information Centres
f) Improve access to Mesothelioma Support Groups
g) Evaluate and expand Benefits Advice Service
h) Establish specialist support & information service for military personnel and veterans.
4 Research, Audit and Evaluation

To help the UK to lead the way in making Mesothelioma history through world class audit, research and clinical trials.

HOW:

a) Increase Mesothelioma UK annual research grants to £1m per annum
b) Fund and support development of sustainable national mesothelioma audit program
c) Repeat National Mesothelioma Patient & Carer Experience Survey
d) Develop regular ‘snapshot’ audit programme
e) Facilitate the establishing of UK Meso Research Network
f) Develop Mesothelioma UK evaluation process
g) Provide Funding to support patient participation in non-commercial clinical trials

5 Prevention and Awareness

To raise the profile of mesothelioma and prevent future cases of asbestos related disease.

HOW:

a) Support the establishing of a National Mesothelioma Coalition
b) Prepare Meso UK key messages info graph
c) To work with corporate partners with awareness campaigns
d) Build relationships with parliamentary colleagues
e) Establish catalogue of patient stories
f) Deliver targeted awareness campaigns (GP’s, practice nurses)
g) Action Mesothelioma Day activities

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Process for Delivering Mesothelioma UK’s 5 year Strategy...

Action Plan
Each year the operational team will develop an Action Plan, highlighting aspects of the strategy to be focused and delivered on during that year.

Individual Performance Appraisal
Operational team members IPR’s will be linked to the charity annual action plan.

Team Meetings
The operational team hold monthly team meetings. The agenda reflects Mesothelioma UK’s core business, each of the charity work streams and annual action plan.

Trustee Meetings
The Board of Trustees meet 4-6 times annually. The agenda contains reports on core business and updates on all projects and bids. Proposals for new development are discussed and agreed through the trustee meetings.

Nurse Specialists
The nurses specialists meet 5-6 times per year. Each meeting has an educational component particularly focused on clinical trials. There is also an opportunity to reflect on practice related matters, the Mesothelioma UK service delivered and any nursing issues that have arisen.

The nurse team meetings also look at the service level agreement (SLA) expectations and enable the nurses to share good practice ideas for meeting the SLA.

Service developments from the Mesothelioma UK strategy and annual action plan are also developed and reviewed.
And finally...

In summary, this strategy – **Dedicated to Making Mesothelioma Matter** outlines the charity’s vision and a route to reaching more people affected by Mesothelioma, to improving peoples experience and importantly the outcome of the treatment and care available.

The Mesothelioma UK team (Trustees, Operational Team, Clinical Nurse Specialists, Ambassadors and Advisory board) welcome your comments and your support in helping make Mesothelioma matter.

Please feel free to contact the charity

**Acknowledgements**

- Mesothelioma UK Operational Team, CNS’s & Trustees
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