

Patient & Family Myeloma Infoday Guidelines

This document is intended to assist in the organisation of a successful Infoday. It is intended for relatively large scale Infodays (attracting between 50-200 patients and family members) and follows the UK model where 8-10 Infodays are held throughout the UK during the course of the year.

It is a guide and is by no means definitive as ultimately, the organisation of each Infoday will be slightly different.

The following are the main steps to organising an Infoday:

1. Venue
2. Chairperson
3. Attendees
4. Programme and speakers
5. Registration
6. Delegate packs
7. Before the day
8. On the day
9. Follow up and evaluation

Venue

The venue should ideally be sourced no later than 6 months prior to the planned date of the Infoday.

Requirements for the venue:

- Main room to have sufficient capacity – with classroom style layout
- 3 breakout rooms
- Disabled access
- Restaurant to accommodate 2-course hot lunch
- Parking facilities (preferably free)
- Close to public transport e.g. train station
- Audio visual facilities – PA system, 2 hand-held mics, lectern, large screen (8ft x 10ft), lectern mic
- Accommodation at the venue or close by for attendees travelling from a distance

Once the venue has been sourced and the costs agreed, you should organise for a site visit to view the venue facilities and the rooms which have been booked to ensure they are suitable for our requirements.

Once this has been completed and everything is acceptable, the venue will send through a contract to review and sign. You should check through this very carefully and mark any changes on the contract.

All details i.e. dietary requirements and final numbers etc should be finalised the week prior to the Infoday.

Chairperson

Once the venue and date have been confirmed, you need to invite a myeloma doctor, preferably in the same town/city as the Infoday venue and invite them to Chair the Infoday. This is usually done by email or letter and more often than not you will approach a doctor with whom you have had prior contact and who has indicated he/she would be willing to give up some of their spare time to attend.

Attendees

The next step is to inform the target audience about this event.

Use your existing database to search for all the patients, family members and friends living in the area and send a flyer/ and or letter to them telling them about the event.

Send all the healthcare professionals in the local area a poster and flyers to display in their clinic and on their noticeboards.

You may also want to advertise in your local newspapers.

Programme and speakers

The Chairperson should be sent a copy of the draft programme for the day and asked to recommend local doctors or nurses to present at the Infoday.

Once they have done this, you need to send out an email inviting each of the speakers to attend and present on a particular topic.

If they accept the invitation, you will need to send them a speaker brief with details of what their talk is about and areas which they should and should not cover during the talk.

The speaker brief should also detail how long the talk is expected to last for and who the audience will be.

The speakers should be sent regular email updates on number of participants signed up to attend and details of any changes to the programme.

The speakers should also be asked to send letters to their myeloma patients and carers to encourage them to attend.

Registration

If someone completes and returns a booking form or makes a booking over the telephone or via the website, you need to process this booking. This will ensure you know approximately how many delegates to expect on the day, although inevitably some will always turn up on the day without registering beforehand.

Confirmation letters, along with a map and directions to the Infoday venue and the programme for the day should be sent out to confirm their attendance.

Delegate packs

Delegate packs should be made up for each attendee at least 3/4 days prior to the Infoday and should include the following:

- Welcome Letter from the organisation
- Final programme for the day
- Speaker profiles (biography and photograph for each of the speakers)
- Publications order form
- A copy of your patient magazine (if you have one) and subscription form
- Literature about your organisation and the services you offer, including any publications about myeloma that you think are relevant
- An evaluation form
- A raffle draw envelope if you want to make a collection on the day

All these items should be collated and put into a clear plastic folder. These packs are handed out to the delegates at the registration desk on the morning of the Infoday.

Before the day

Before the day ensure you have:

- Name badges
- Several attendee lists from which to register delegates on the day
- Sufficient stationery, merchandise and information to distribute on the day
- Methods of accepting payment for those that are paying on the day (if you are charging a nominal fee to cover costs of the venue)
- Delegate packs finalised
- Breakout session room signs

Also ensure that you have enough staff or volunteers from your organisation available to attend the day and that you have arranged for you all to get there. Infodays with 100 attendees should ideally have 4-5 volunteers helping out on the day.

On the day

We have provided a draft programme for an Infoday. This can vary, but it provides an idea of the types of topics that might be covered throughout the day.

You may also want to take along your range of publications and make them available on an information table for people to look at and take away.

Draft Programme

8.45am-9.30am - Registration and coffee on arrival

Morning sessions – presentations about myeloma and its treatment

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| 09.30 – 09.45 | Welcome & Introductions |
| 09.45 – 10.15 | Understanding myeloma – doctor to present for 20 mins and 10 mins of questions from the audience |
| 10.15 – 10.45 | Overview of standard treatments approaches - doctor to present for 20 mins and 10 mins of questions from the audience |

Morning tea / coffee break

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| 11.15 – 11.45 | Vertebroplasty/kyphoplasty treatment in myeloma – doctor to present for 20 mins and 10 mins of questions from the audience |
| 11.45 – 12.15 | Living with myeloma / psychological care – A nurse to give a presentation of 20 mins and 10 mins for questions |
| 12.15 – 1.00 | Patient / Carer experience – where people talk about their experiences of living with myeloma |

Afternoon sessions – focusing on sharing experiences and learning about myeloma in smaller groups

Lunch and opportunity to talk with others informally over tea and coffee

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| 2.30 – 3.45 | Meet the Experts & Carers' Sessions
Meet the Doctor
Meet the Nurse
Carers' session |
| 3.45 – 4.15 | What's on the horizon? – All about new treatments, presented by a doctor and with questions from the audience |
| 4.15 – 4.30 | Final comments, summing up and close of day |

Follow up and evaluation

Follow up is extremely important so attendees to the Infodays feel that they have not been to a one off event but rather have a support network where they can then stay in touch and continue to get information and support.

A letter can be sent those who attended informing them of other services you may offer or information you may provide. For those that expressed interest in attending but couldn't, send a delegate pack so they can learn more about the topics discussed at the Infoday.

You may also want to include an evaluation form to all of the people attending on the day to get their feedback on what worked and what didn't. This can be very helpful for you when planning future Infodays.

Also don't forget to thank the doctors for attending and giving up their spare time to help.