

**Using the Quality of Life Principles:
A Programme Planning Workbook
for MS Societies**

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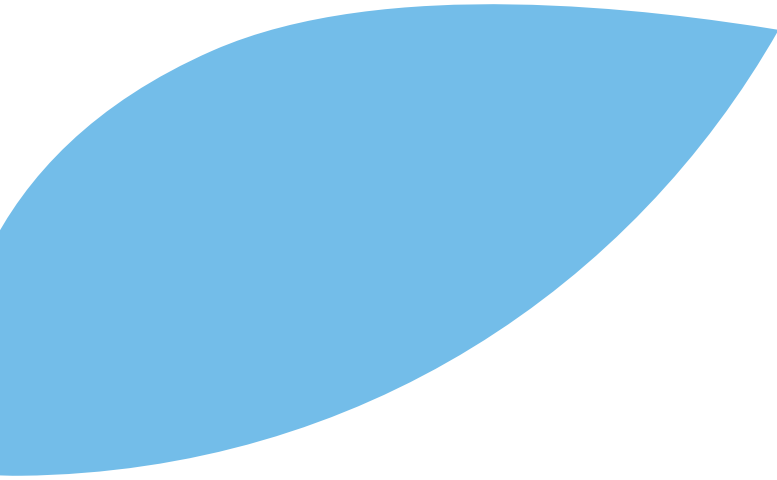
multiple sclerosis
international federation



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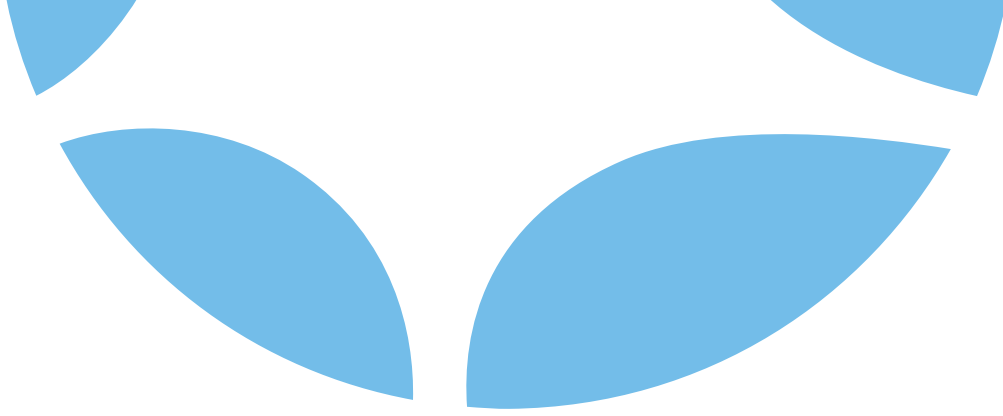
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What is programme planning?

Programme planning is a way to identify and move toward desired future states. It is a management tool that helps an organization focus its energy, ensuring that members of the organization are working towards the same goals. It helps an organization to assess and adjust its direction in response to a changing environment.

Most programme planning methodologies are based on a process that includes assessment and decision-making about priorities and action steps:

- 1. Situation**
 - Where are we now?
- 2. Target**
 - Where do we want to be?
- 3. Path**
 - How can we get there?


Programme planning helps us to create a vision and set goals for the future.

How do the Quality of Life Principles offer support?

The MSIF quality of life document is a set of principles, each of which has the potential to make a difference for people with MS and their families. In defining the elements that are critical to quality of life, the principles also provide a foundation for MS Societies in planning for programmes and advocacy. In essence, each principle provides a benchmark, against which each Society can compare the practices in its own country. Looking at the document in its entirety, however, can be somewhat daunting.

No country, certainly, provides the ideal environment for people with MS that this document describes. Societies in different countries will relate to the principles uniquely. What may seem like an achievable goal in one country may seem far out of reach in another.

This programme planning workbook is designed to help you to make decisions about what are the most important principles for your Society to work towards in the next 3-5 years, and what you will do to help make those principles a reality in your own country.



The principles are high-level goals. It is not realistic to think about trying to accomplish all of the goals at once. Nor is it realistic to think that Societies can address all of the needs of people with MS by themselves. Each country will develop its own objectives related to those goals, and each Society will need to determine who to engage in programme partnerships and collaborations to establish and achieve their objectives. Situations and opportunities will differ greatly from one country to another.

The workbook provides a process to:

- 1.** Relate each principle to the environment of your own country, assessing current gaps and barriers
- 2.** Evaluate opportunities: assessing the potential your Society has to make a difference in progress towards each principle
- 3.** Establish a vision and priorities
- 4.** Determine objectives
- 5.** Define action steps

Who should be involved?

Senior staff and key leadership volunteers should be involved in the programme planning process. In addition, you may want to invite persons external to the Society who can offer expertise in critical areas (e.g., expertise in your country's health care system or legislative processes) that your staff and volunteers may not possess. And, you will want to identify potential partners: those who might join with you in working towards better quality of life for people with MS.

Developing a programme plan: a five step plan

Included in these implementation guidelines is a programme planning template.

The outcome of this process will be a plan that concentrates a Society's efforts in activities that have the most potential to make a difference for people with MS and their families.

By using this process you will be able to:

- 1.** Analyze each principle in terms of importance, feasibility and potential for your Society to influence positive change
- 2.** Articulate your vision
- 3.** Make decisions about priorities on which to concentrate your efforts
- 4.** Determine objectives
- 5.** Develop an action plan

Preparing for programme planning

Programme planning is best accomplished when the right people are brought together, with adequate time set aside to complete a thorough and thoughtful process.


To set the stage:

Identify key participants.

The leadership of your Society will determine who should be at the table for this process. Participants could include board members, CEO and key leadership staff, people with MS and carers, health care professionals, and experts from industry and government.

Set aside time to meet and use that time wisely.

Programme planning takes time. It is best accomplished in a retreat setting where everyone is away from their daily responsibilities and can fully concentrate on the planning process. Set aside at least a full day for meeting and discussion. (A day and a half is ideal.) We propose that you ask participants to complete the analysis portion of the process as pre-meeting work. Appoint a person to collate the input from all participants, and to use the aggregate data to complete the ranking form.




This form, which shows the rankings of the principles, will be the basis for priority setting. You may want to send the completed ranking form to participants ahead of the meeting, so they know the thinking of the group when they arrive.

As you will be doing a 3-5 year plan, your process should take place early in the planning cycle for the year before you expect to begin implementation.

Complete an environmental scan.

The environmental scan helps to set the scene for the group. You want the perspectives of many, so you will bring together a diverse group. At the same time you may want to provide information that can help everyone to begin the process from the same foundation. “Scene setters” can be reading materials (sent to participants ahead of the group meeting) or presentations from experts to begin the meeting.

(NOTE: If you are setting aside time for presentations as scene setters, expect that your meeting will take more than a single day, as you will still need a full day for the planning process.)



The environmental scan provides data to answer questions from the participants about the present and future situations for people with MS.

The environmental scan:

- Develops common perceptions
- Identifies strengths, weaknesses, trends, and conditions
- Draws on internal and external information

Examples of scene setters that might be used in your environmental scan include:

- Results from client surveys
- Reports from research
- Statistics or other data
- Presentation on status of health care or government priorities
- Report on state of health care
- Perspective of MS clinician on issues facing people with MS and their health care providers
- Reports from staff and/or people with MS on current issues and challenges



Identify a skilled facilitator.

The skill of the facilitator you choose will be a major factor in the success of your planning process. Ideally, you want to find someone who understands the business of not-for-profit or charitable organizations, but is not a member of your team, or a stakeholder in your organization.

Your results are likely to be better if someone other than a team member or the CEO acts as facilitator. You will want your facilitator to understand your issues, but not to be invested in them, or to come to the meeting with preconceived ideas or his/her own agenda. It is essential that this person have experience facilitating group process, and the ability and background to command the respect of the Society leadership.

Expectations of the facilitator include:

- Working with the Society leadership in planning the meeting, developing the agenda, and identifying desired outcomes
- Managing the agenda and the time clock for the meeting; adapting as needed
- Listening to participants, clarifying and summarizing, connecting and organizing themes
- Understanding and clearly communicating tasks
- Managing the group process and keeping the group focused
- Asking appropriate questions
- Ensuring that the thoughts of all participants are heard, and that no one individual dominates
- Building rapport
- Managing conflict
- Working with leadership to finalize the process and report back to participants

Step one:

Analysis

The analytical phase of programme planning is about taking stock of the current status of people with MS in your country and using the principles as a benchmark for comparison.

In this phase you will ask each participant to provide his/her perspective on the separate principles, based on his/her own knowledge and the information provided through the environmental scan. Instructions are provided with Worksheet #1. In this process, each principle is examined to determine:

- 1. The actual status of the principle in your own country.** Is the implementation of the principle completed to a large extent, or not at all—or somewhere in between?

2. Importance to people with MS and their families.

What do your own constituents tell you about what they want and need?

are evaluating the potential of the efforts of the Society itself to make a difference, not just the potential for change that might exist.

3. The potential or opportunity in your country for your Society to influence progress towards the implementation of the particular principle.

Factors to consider include the possibility of partnerships or collaboration, the availability of public support, the Society's ability to influence public policy and/or health care systems, as well as the potential of the Society itself to implement a programme or service. Remember that you

In this analytical phase you want first to get the perspective of individuals, and then come to group consensus. Ideally, individuals complete and submit their analysis worksheets for each principle prior to the programme planning meeting. The ratings are collated and ranked in three ways, using the averages of the ratings submitted by all participants.

It is these ranked listings that you will use to begin priority setting. (See templates.)

Ranking the analysis sheets for the principles.

Sort the worksheets received from each individual into stacks by principle. One principle at a time, add the scores for each of the elements (the rankings for “status of implementation,” “importance,” and “potential/opportunity” that you received from each individual) and then divide each score by the number of responses to determine an average score.

Rank the principles in order of their average scores, highest to lowest, in the three columns on Worksheet #2.

Highlight principles that rank near the top in all three columns.

NOTE: You can also total the averages of all three aspects for each principle and rank those scores.

Step two:

Articulate a vision

If you could look into a crystal ball, and see a better future five or ten years from now for people affected by MS, what would it look like?

In this step of the planning process, you will create a vision statement. Ask the question, “What is our preferred future?” Write the statement in terms of people whose lives are affected by MS, and what you hope will be different about their quality of life. While a vision statement should have some basis in reality, it is more than acceptable to envision something that may seem like a significant stretch from where you are today.

As you formulate your vision for the future, be sure to:

- Draw on the beliefs, mission, and environment of the organization, and the quality of life principles
- Be specific to your Society and your country
- Be positive and inspiring
- Do not assume that your organizational system will have the same framework as it does today
- Be open to dramatic modifications to current organization and methods
- Phrase your vision in terms of future oriented goal statements (e.g., people with MS will have...)

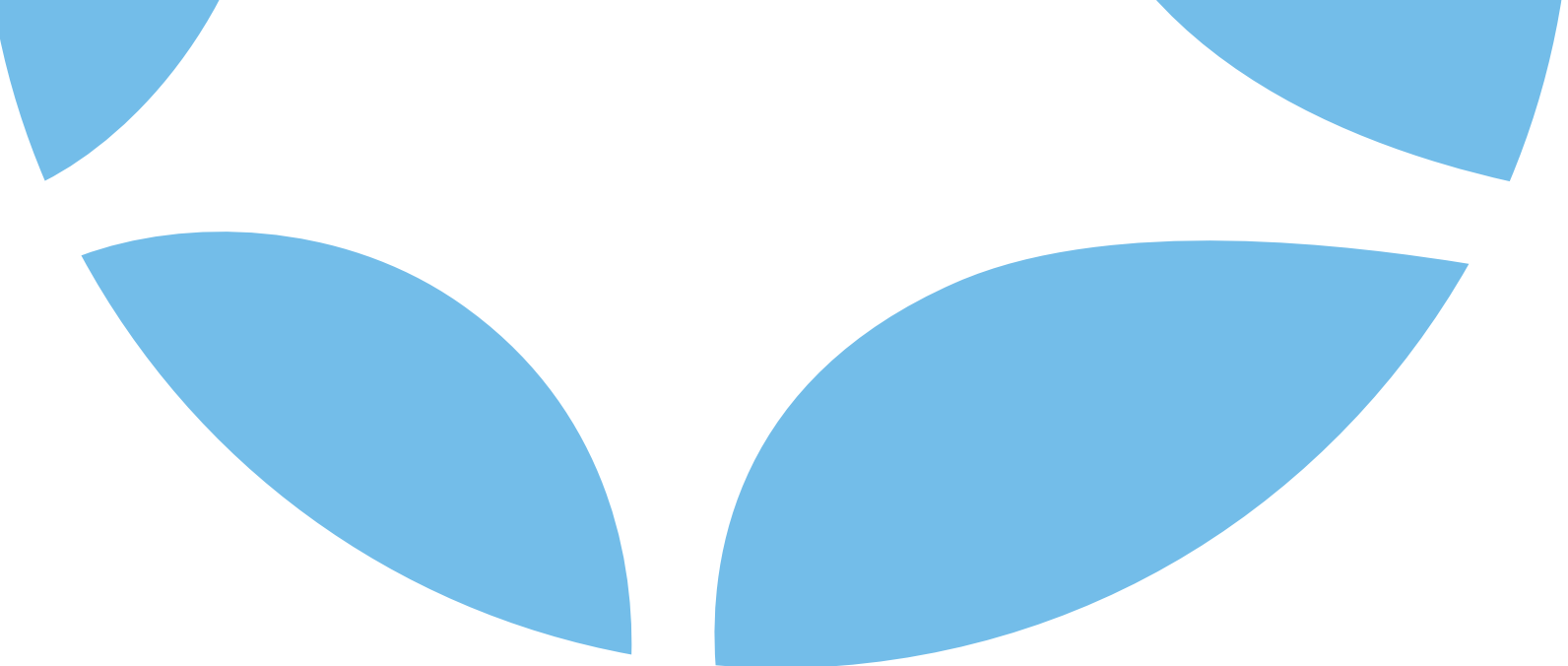
Write your vision on Worksheet #3.

Step three:

Establish priorities

In this part of the programme planning process, you will determine the top priorities for your Society's efforts for the next 3-5 years related to improving quality of life for people with MS. Priority setting is a critical part of programme planning—and maybe the most difficult. It is often easy to see the gaps and the needs, but much harder to acknowledge that it is not possible for any organization to address all of those needs. Setting priorities helps us to focus our efforts on those areas that have the greatest potential—so that our work makes a difference in the lives of those we serve.

Your vision statement and the completed Worksheet #2 (showing how your programme planning team ranked each of the principles in terms of the current state of implementation, importance to people affected by MS and potential for influencing change) will together serve as the springboard for your discussion. The planning facilitator should ensure that participants are aware the ranking sheet is only meant to be a tool. The group must relate the principles to their vision, and come to consensus on what are the most important principles for which the Society will dedicate new efforts and resources over the next few years.




But priority setting is different from visioning. The analysis you have done will help you to examine your vision not only in terms of the needs of people with MS in your country, but also in terms of what is realistic and practical.

The planning facilitator should help identify those principles that rank high in each column on Worksheet #2—with particular attention to those which ranked high in all—and then conduct an open discussion, seeking input from all participants. It may help to look at the list of principles in terms of the dedication of time and resources needed.

- For which principles should the Society increase the time and resources dedicated to implementation?
- For which principles should the efforts continue at the current level?
- And which principles are seen to be beyond the scope of the Society's current influence, less important or already in place, for which the Society will dedicate little time or resources in the upcoming few years?

For programme planning purposes, focus on those priorities for which increased effort and/or new direction is determined to be important and feasible. For these priority goals, you will formulate objectives.



How many priority goals a Society should establish will vary from one country to another.

Consider the following:

- The resources and readiness of your Society
- Infrastructure, including the ability to mobilize staff and volunteers
- The Society's community influence and outreach
- The complexity of challenges that your top priorities present

Well-established Societies with secure funding sources and staffing structure, stable infrastructure and community presence might take on up to eight or ten principles as priorities to address. A younger, volunteer-driven Society might realistically only be able to work on one or two priority goals. Remember: if everything is a priority, nothing is a priority. It is important to make the right choices about where and how to focus the Society's efforts.

Your ability to fully achieve your vision and priority goals may extend beyond the 3-5 year planning period, but your objectives should represent progress towards these goals that you realistically hope you can achieve during the period of the plan.

Step four:

Determine objectives

Objectives are statements about desired changes. As you have gone through the stages of preparation and analysis, you have essentially conducted an audit of your current situation, and compared the current practices in your country with the benchmark each principle provides. In articulating your vision and setting priorities, you have identified critical areas with potential for change.

The difference between where we are (current status) and where we want to be (vision) determines what we do (target objectives and action plans).

Objectives are simply clearer statements of the goals you articulated in your vision, specifying the accomplishments to be achieved if the vision is to become real. Phrase your objectives in terms that are outcome-oriented. Think about how you may be able to measure your outcomes as you establish objectives.

You should have at least one objective for each priority goal you have established. Each objective will relate to one or more of the quality of life principles.

You will use Worksheet #4 for establishing objectives and action steps. Use a separate sheet for each objective.

Step five:


Develop an action plan

In developing an action plan, you will choose specific activities that have the potential to accomplish your goals and objectives. You will want to have action steps for each objective.

While goals and objectives are strategic and address desired future states, action steps are concrete and operational. Action steps must be realistic and achievable within the established time frame, within the resources of the Society and community.

It is best to establish action steps for 1-3 years. As what you do in subsequent years is dependent on the successful implementation of the first steps, it is hard to realistically plan operations long range.

Some Societies may want to end the initial programme planning session at objective setting, and establish a second phase that engages those who will be directly involved in implementation. This may work best for Societies with layers of professional staff who may not all be involved in the planning retreat but will want to be involved in developing their own work objectives.



It then becomes the responsibility of staff to establish the action steps to achieve objectives as a part of their annual operational planning process.

Other Societies may find it beneficial to use this planning retreat to determine the action steps. This works very well when the volunteers and staff who are a part of the planning process will also be the implementers. It is particularly important if the programme planning is not driven by the Society alone, but is a collaborative effort with other community partners.

Action steps should have a 'who' attached. Who will ultimately be responsible for the implementation of the activity? The 'who' may be a Society staff person or volunteer, or a person from the community, who steps up to take the responsibility for the activity.

Implementation, follow up, and outcome measurement.

Action steps come to life as they are integrated into the organizations' operational plans. How each Society accomplishes bringing the programme plan into fruition will vary depending on organizational structure

and staffing. But in every organization, if plans are to become reality, appropriate human and financial resources need to be allocated. At least one person, whether staff person or volunteer, must accept responsibility for driving the progress of each action step — including the development of timelines and monitoring of progress towards the established objectives.

Many Societies already have established systems for programme outcome measurement and evaluation that will work very well in the programme planning process. Those countries looking for

programme evaluation models can consult with MSIF staff, who can share models that are already being successfully implemented in other Societies.

As a part of the project, the MSIF will be establishing new opportunities for the sharing of best practices in programmes and advocacy. This helps us to learn from each other to find ways to enhance the quality of life for people with MS around the world.

Worksheet #1:

Analysis of principle

Please circle the number in each box that, in your opinion, best describes the relationship of this principle in our country, today.

Quality of life principle to be addressed #

Status of implementation of this principle in our country today						
To a very large extent (little change needed)	To a moderate extent			To a very small extent or not at all (much change needed)		
1	2	3	4	5	6	7

Importance to people whose lives are affected by MS in our country						
Less important than most other issues	Important			One of the most important issues		
1	2	3	4	5	6	7

Current opportunity/potential for progress towards implementation of this principle						
Little or no current potential	Some possibilities exist			Significant opportunity exists		
1	2	3	4	5	6	7

Worksheet #2: Summary of participants' ranking of principles

Implementation of principle (rank highest to lowest)	Importance of principle (rank highest to lowest)	Opportunity for progress in implementation of principle (rank highest to lowest)	Ranking when averages are totaled (rank highest to lowest)

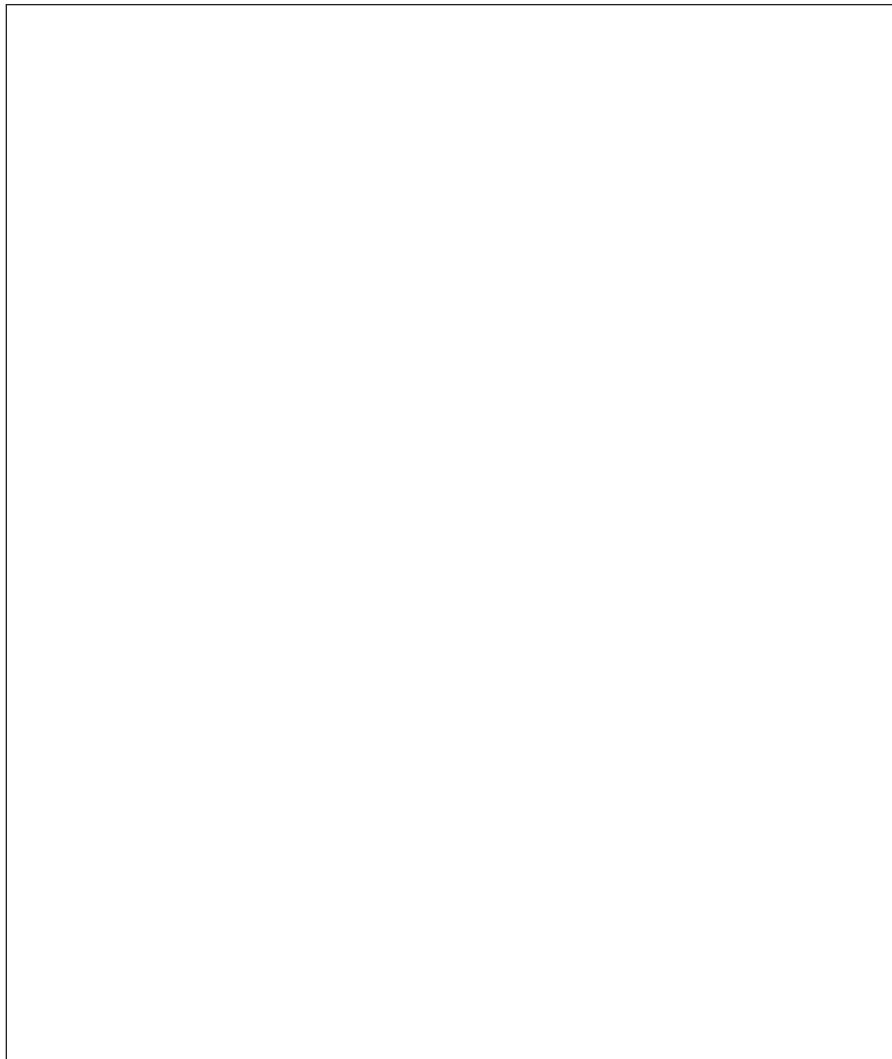
Worksheet #3:

Top priorities for change

List in order of priority, the quality of life principles on which you will focus your most significant effort over the next 3-4 years. (Note: You may choose fewer or more than eight.)

- 1.
- 2.
- 3.
- 4.
- 5.
- 6.
- 7.
- 8.

Worksheet #4: Vision statement

A large, empty rectangular box with a thin black border, intended for the student to write their vision statement.

Worksheet #5: Objectives and action steps (one for each objective)

Quality of life principle to be addressed

#

Objective

Action Steps	
Year One 1. 2. 3.	Who
Year Two 1. 2. 3.	Who
Year Three 1. 2. 3.	Who

The background is a solid light blue color. It features several large, dark blue, abstract shapes that resemble stylized leaves or petals. One large shape is in the upper left, another is in the upper right, and a third is in the lower right. There are also smaller, partial shapes at the bottom right and top right.

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MSIF would like to thank Biogen Idec for their generous grant which made the production of this publication possible.