



## MCA Cancer Plan Revision Meeting Summary

### Survivorship Workgroup

11:30 a.m. – 1 p.m., April 27, 2016

**Participants:** Tia Bastian, Anne Blaes, Lynn Everling, Shari Hahn, Kristen Kopski, Liz Moe, Scott Nelson, Syndal Ortman, Katie Ruddy, Lindy Yokanovich

**MDH Staff:** Maggie Maggio, Jeanne Steele

**Location:** Hope Lodge, Minneapolis, MN and by conference line

| Agenda Topic                       | Key Points Raised  | Next Steps   |
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| <p>Introductions &amp; Welcome</p> | <p>The co-chairs thanked everyone for coming or calling in and invited participants to introduce themselves and explain their interest in survivorship. They explained that two members, survivor advocate Ruth Bachman and physiatrist Nancy Hutchison were unable to attend because of pre-standing commitments.</p>   | <p>NA</p>  |
| <p>Background</p>                  | <p>The Minnesota Cancer Alliance website is the go-to-place for information about the update process. Resources of interest to all of the workgroups can be accessed by scrolling down the <a href="#">Cancer Plan Update</a> page and clicking on the <a href="#">Core Resources</a> and <a href="#">Data</a> link at the bottom of the page. Each workgroup also has its own page where meeting summaries, meeting dates and documents that pertain to the workgroup’s focus area will be posted. Each workgroup page provides a place for feedback where people can share their opinions and offer suggestions about what they would like to see in the next state cancer plan.</p> <p>The next plan will be a 10-year plan with emphasis on aligning forces during the first 5 years, on identifying who can and should come together to make change. It is envisioned as a dynamic plan that will change over time. Workgroups are urged to look at cross-cutting issues and how survivorship fits into those issues.</p> | <p>Send documents you would like posted to Jeanne Steele, MDH staff liaison for survivorship (<a href="mailto:Jeanne.steele@state.mn.us">Jeanne.steele@state.mn.us</a>).</p> <p>Encourage stakeholders and advocates to post questions and comments on the Survivorship Workgroup page on the Web.</p> |

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| <p>Survivorship Issues that should be included in next plan</p> | <p>Syndal led a discussion about what issues the workgroup believes should be addressed. She suggested that Objective 18 (Connect cancer patients and caregivers with non-clinical support services) and Objective 19 (Provide cancer patients with a comprehensive care summary and follow-up plan after completing treatment) in the current plan remained important. There was broad agreement that both should be retained in some form.</p> <p><u>Discussion about resources:</u></p> <ul style="list-style-type: none"> <li>• Lots of underutilization – due to access barriers or lack of knowledge?</li> <li>• Should think about resources broadly and include nutritionists, chaplaincy, transportation, physical activity resources (for prevention, too)</li> <li>• Patients come to Cancer Legal Line through social workers, but how do they get to a social worker?</li> <li>• Cancer Alliance used to have a great website, like a MN cancer yellow pages, but it just became too unwieldy to manage and keep updated, so it went away</li> <li>• Flip side is providers of some resources feel like they're waiting for patients</li> </ul> <p><u>Defining survivorship:</u></p> <ul style="list-style-type: none"> <li>• Should the conversation be structured into differing phases? Needs during treatment? After conclusion of treatment? Longterm – for the rest of life?</li> <li>• NCI definition is from the time of diagnosis forward</li> <li>• Will probably touch on all different phases because that's the nature of survivorship.</li> </ul> <p><u>Scope of work:</u></p> <ul style="list-style-type: none"> <li>• Need to be careful about overlapping with other groups like Prevention and Treatment</li> <li>• We will be advocating for pts done with treatment or transitioning out of treatment, which is a difference from the other groups.</li> <li>• Overlapping with other groups isn't bad, cross-cutting is what we want in this conversation.</li> <li>• In past, end-of-life issues were handled under survivorship</li> <li>• Palliative care could easily go into treatment</li> <li>• Palliative care needs to be addressed by us because it dovetails with what we're doing.</li> <li>• Advance care planning is a huge topic and concern, but we can't give it the time and attention it deserves – and it doesn't make sense to start making an advance care plan when someone is transitioning from active treatment because it's already so stressful.</li> </ul> | <p>Need to look more closely at how following issues should be addressed:</p> <ul style="list-style-type: none"> <li>• Physical rehabilitation.</li> <li>• Financial toxicity associated with cancer diagnosis.</li> <li>• Importance of advance care planning and palliative care (If not covered elsewhere, it's something we might take on.)</li> <li>• Extra/heightened concerns for patients in rural areas who need to drive long distances for most everything related to their care.</li> </ul> <p>Things still to be discussed:</p> <ul style="list-style-type: none"> <li>• Needed support systems, e.g., for caregivers.</li> <li>• Insurance issues – need more payers to get involved. A group made up of consumers, care providers and insurers would have more muscle.</li> <li>• Patient navigation is a critical issue</li> <li>• Role of technology</li> <li>• Potential partners we haven't thought of yet</li> <li>• Measurement and evaluation – How will we measure the impact of what we're planning?</li> </ul> |
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|  | <ul style="list-style-type: none"> <li>• It would be nice to take a more systemic approach, where everyone has an advance care plan. This would be a great thing for the state to work on. Even with Epic or Care Everywhere, providers can't see what's in other electronic health record systems. The state could set up some kind of reporting system (like the MICC – MN Immunization Information Connection, or PMP – Prescription Monitoring Program), or a registry indicating there's a record and where to obtain it.</li> </ul> <p><u>Physical Medicine and Rehabilitation (PM&amp;R):</u></p> <ul style="list-style-type: none"> <li>• Nancy Hutchison, who could not participate because she was in clinic, sent notes cautioning that MN may fall behind nationally if it doesn't step up and do more to integrate PM&amp;R as an essential component of cancer recovery.</li> <li>• She says a whole other spectrum of people (cancer exercise trainers) that need to be involved.</li> <li>• In addition to PM&amp;R, the literature talks about the importance of physical therapy, occupational therapy, speech therapy and nutrition therapy.</li> <li>• Education for physicians and survivors is inconsistent.</li> </ul>  |  |
|  | <p><u>Community resources:</u></p> <ul style="list-style-type: none"> <li>• Silver Sneakers, wonderful insurance benefit included in many Medicare plans. Available in Rochester, not in Twin Cities.</li> <li>• "These programs are great, but we need a reliable way for patients to know about reputable resources and a way for patients to access the resources."</li> <li>• Access is a really huge problem for people in rural areas.</li> </ul> <p><u>Policy, systems and environmental change opportunities:</u></p> <ul style="list-style-type: none"> <li>• Problem should be treated in terms of policy. Bring in deans of medical schools to talk about how to train providers. Talk about certifications for specialists like a special tag for cancer PT/trainers, and so on.</li> <li>• From a broad perspective we want to include partners like insurance companies. Cardiac rehab is included in insurance, but cancer PT isn't. Great opportunity for PSE changes.</li> <li>• For people in rural areas maybe we should consider online classes for PT or different ways of accessing resources. Tech groups are currently working on and incorporating that technology. How do we incorporate that?</li> <li>• Financial fallout from cancer can't be overstated. Bankruptcy numbers are through the roof. Recent study shows that 30% of women diagnosed with breast cancer who are employed at the time of diagnosis aren't working 5 years later.</li> </ul> |  |

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|            | <ul style="list-style-type: none"> <li>• MN has high insurance coverage, but 14% are on a high deductible plan which makes people put off treatment. High cost is destroying the middle class. We should go bold on this to make MN a safe haven. Not just health insurance, also disability insurance. Lots of providers are busy and can't take the time to fight for patients or don't know how to fight for pts, which isn't necessarily something they should be doing. Social security shouldn't be 5 months until a payout.</li> </ul> |  |
| Next steps | <p>The group will start working on the following:</p> <ul style="list-style-type: none"> <li>• Support Services</li> <li>• Survivorship Care Plans (in the broad sense of content, hand-off, and accessibility)</li> <li>• Physical Rehabilitation</li> <li>• Financial/Insurance Issues</li> <li>• Palliative Care services</li> <li>• Patient Navigation</li> </ul>   | Syndal will send template and instructions to guide efforts. |

**Next meetings:** May 18 and June 22, 11:30 a.m. – 1 p.m.

**Between meeting assignment:** Choose topic area you're passionate about and complete worksheet (forthcoming). Co-chairs will send out a template to complete. Workgroup members should pick "something they're passionate about," collect information and input, and plan to come together to share on May 18.