THE MONTANA CAREGIVER ACT:
Hospitals Helping Caregivers in Montana and Nationwide

MHA
Montana Hospital Association

AARP
Real Possibilities
The Montana Caregiver Act – HB 163

- Takes effect October 1, 2017.
- Better involves family caregivers when their loved ones go into the hospital and as they transition home.
- Ensures that caregivers have what they need — such as instruction on managing medication regimes, wound care, and other medical/nursing tasks — to help care recipients at home.

HB163 – the Montana Caregiver Act - was introduced in the Montana Legislature during the 2017 Legislative session by Representative Geraldine Custer a Republican legislator from Forsyth. The bill was introduced at the request of AARP Montana. The bill passed the Montana House on third reading with a vote of 97 yes and 3 no. The bill passed the Senate unanimously from committee to the floor.

HB163 was signed into law on March 31, 2017 and has an effective date of October 1, 2017.

The intent of the act is to “better involve family caregivers when their loved ones go into the hospital and as they transition home.”

The legislation ensures that caregivers have what they need to help care for these individuals when they return home — this may include instructions on managing medication, wound care, activities of daily living, and other medical/nursing tasks that do not require a licensed professional.
Good afternoon everyone. My name is Glen Fewkes. I'm a Senior Legislative Representative in AARP's Government Affairs Department based out of Washington DC.

Thanks especially to the Montana Hospital Association for holding this webinar and allowing me to participate and have this discussion with others who care about these issues and implement them on the ground. I greatly appreciate all of the incredible work that you do.

I work in AARP's National Office as part of the internal policy and advocacy support team for our state offices. AARP has offices and advocacy staff in all 50 states, DC, Puerto Rico and the Virgin Islands.

I have the pleasure of working very closely with AARP Montana on issues regarding family caregiving, long-term services and supports, and health issues generally. Some of you may know Tim Summers, our state director here and Claudia Clifford, our advocacy director who do great work along with their other staff based in Helena.
• I’m especially excited this afternoon because I get to talk with you about the Montana Caregiver Act [that Dick just mentioned].
• I have been involved with AARP Montana and MHA and others as this bill was devised over the last couple years and then eventually passed this year; I think it will prove to be a great support for family caregivers in Montana.
• I know the big questions on your minds are: What does this mean for me? What is required? What do I need to do?
• And I promise that we’ll get there, but I think first it would be helpful to give a bit of background of where this law came from and why we feel it is so important in the state.
• First, just to lay a foundation, AARP’s most recent estimates are that there are 40 million family caregivers in the country who provide 37 billion hours of care each year.
• And of course, sometimes I will use the term “family caregiver” but this can mean a relative, a neighbor, a friend; it doesn’t need to be a blood relation.
• Just in Montana alone, there are around 118,000 family caregivers who provide 110 million hours of care each year.
• And this means anything under the sun to help their loved ones live independently at home.
  • From personal, intimate activities like bathing or dressing, helping administer medicine, to more common tasks like helping pay bills and managing finances or scheduling and accompanying a loved one to doctor appointments.
• Most of these things are done on an unpaid basis, but if you tallied up the value of all of that care, it would be approximately $470 billion nationally and $1.4 billion in Montana.
• How big is that?
  • Roughly the same as Walmart’s annual sales worldwide.
  • And importantly, more than the country’s entire Medicaid budget for the year.
Meet the Montana Caregiver

The Average MT Lay Caregiver:
• 55 years old or older
• Female (59%)
• Married or living with significant other (75%)
• College educated (55%)
• Working full- or part-time (50%)
• Annual household income of less than $60,000 (56%)

Late last year, AARP Montana conducted a survey statewide to find out more about family caregivers in the state and get a better feel for their opinions on a few things.

Of course, it goes without saying that caregivers come in all stripes, but here’s what we found out about the average Montana caregiver:
• The average Montana caregiver is 55 years old or older, and
• the majority are female (59%),
• married or living with significant other (75%),
• is college educated (55%),
• working full or part-time (50%),
• and has an annual household income of less than $60,000 (56%).

Nationally we know that the majority provide an average of 20 hours a week of care and others care for their loved ones 24 hours a day, seven days a week.

The picture here is of Tessa, a Montana resident, and her father. Tessa has been caring for her 87-year-old father for 4 years. There are 118,000 other caregivers just like Tessa in the state.
A few years ago, AARP teamed up with the United Hospital Fund to do a study that we call “Home Alone.” For the Home Alone report, AARP surveyed family caregivers across the country to get a look at the type of help they’re providing. What we found is that they’re providing much more complex care than many had thought:

- **Nearly half** are performing some kind of medical/nursing tasks or medication management.
- **Most did not get any training** to perform these tasks.
- Most care recipients (69 percent) did **not have home visits** by a health care professional.
- Understandably, family caregivers performing medical/nursing tasks were most likely to report feeling *stressed* and worried about making a mistake.
- **More than half reported feeling down, depressed, or hopeless** in the last two weeks, and more than a third reported fair or poor health. These negative impacts increased with the number of the care recipients’ chronic conditions.
I don’t think anything in this study was a huge surprise, but this study really got the ball rolling on this issue for AARP internally.

- Of the medical and nursing tasks being performed by family caregivers, the vast majority are performing medication management, whether that be oral, intravenous, or injectable meds. Almost half were administering five to nine prescription medications a day. Medication management was reported to be difficult because it took so much time, it created anxieties about making a mistake, and some care recipients were uncooperative.
- They’re also helping out with assistive devices, preparing special diets, doing wound care, and many other things.
- Family caregivers are performing tasks in a home environment that could even challenge professionals.
• This is clearly a need, so the question becomes what can be done to help and WHEN?
• As you all know well, in the world of healthcare and long-term care, some of the most important times are when people are transitioning between settings and providers. So, for example, between the ER and the normal hospital, or between the hospital and a nursing home. These are key points when, if things don’t go well, it can mean some pretty bad outcomes for patients.
• Every couple years, the Healthcare Intelligence Network does a survey of hospitals to ask them about care transitions.
• When asked what was the most critical transition of care, 50% of hospitals said that it was the transition from hospital to home. Far and away, hospitals see this as the most important transition.
• So that’s where we decided to focus, to improve this transition, and better prepare caregivers as they participate in this transition.
• Not all caregivers will get **paid assistance** at home, and those who do may not get it for a few days. No matter what happens down the road, caregivers need to be **better prepared** as their loved ones leave the hospital.

• Now, I recognize that in large part, I'm preaching to the choir here. No doubt many hospitals in Montana and around the country are doing an excellent job of involving family caregivers in the discharge process and we've heard of some really great experiences of family caregivers in this area. The real point of this Caregiver Act effort is to build on existing practices and make this experience the norm across all hospitals and for all patients.

• As many of you have probably noticed, the industry seems to be already moving in this direction, with various transitional care demonstrations and models out there, and the proposed federal hospital discharge requirements that call for more involvement of family caregivers.
As part of that survey I mentioned earlier, AARP Montana asked what the public thought about these kinds of helps and supports for caregivers at the time of hospital discharge. Other states were adopting these kinds of laws, and we wanted to know what Montanans thought of that.

You see here, the public support is just incredible. 92 percent support instructing caregivers on the medical and nursing tasks they will need to perform at home. And you see there’s also very high support for the other elements of the law.

And the incredible thing is, this high level of support was true across all political party affiliations and ideologies. Caregiving really is one of those issues that unites people rather than divides people.

We get it, we understand it, we’ve lived through it, our families have worked through it.
In 2013, AARP put together a model bill that states could use as a basis to craft their own bills that help address this issue. We called this model the CARE Act (caregiver advise, record, and enable act) and this is what Montana used as the starting point for its bill, the Montana Caregiver Act.

And because there is no point in doing this if there isn’t buy-in at the state level, AARP worked very closely with legislators, MHA, and others to make sure Montana pursued a version of this bill that makes sense for this state, and we really appreciate that collaborative spirit from your organization.

Truly, many Montana hospitals were already doing a lot of what is required even before this bill, but this law makes sure all patients and caregivers are getting these needed supports.

We’ll spend more time in a minute going over the details of the law, but in general it does three simple things:

- When a patient is admitted, they are given the opportunity to designate a family caregiver and have that person’s information documented.
- If the patient does designate a caregiver, that person is contacted prior to discharging the patient or transferring the patient to another facility.
- And finally, the caregiver is given a chance to consult about the discharge plan and to receive instructions on the specific follow-up care tasks that the caregiver will need to carry out at home and to ask questions about the tasks.
Currently there are 39 states or territories that have enacted a similar law (the red states with the little heart).

The dark grey states are ones where the bill has been introduced and we’re still working on it.

Given that the CARE Act has only been in existence since 2014, we think this is a pretty good showing and a clear sign that this is needed. On top of that, take a look at the mix of states that have passed the CARE Act. This is clearly not a red or blue issue, this is a human issue that a lot of people can get behind.
And finally, here's a nice picture of the bill signing earlier this year with Gov. Bullock. AARP's Tim Summers and Claudia Clifford are pictured, as is MHA's Casey Blumenthal, and one of the main sponsors, Rep. Geraldine Custer. As with all legislative efforts, there were a lot of individuals and groups involved that made this happen. MHA's early input and eventual support was a huge factor in passing a bill that is workable for Montana's hospitals and caregivers.
Caregiver Designation

• Each hospital inpatient (or his/her legal representative) is given the **opportunity to designate** a “lay caregiver” who will provide aftercare assistance to the patient in the patient’s residence after discharge.
  – The patient’s “residence” does not include nursing facilities, assisted living facilities, group homes, or similar settings.
  – A “lay caregiver” may not be someone who receives third-party payment (other than Medicaid self-directed programs).

• If the patient designates a lay caregiver, the hospital requests the patient’s **written consent** to release medical information to the caregiver.

At long last we’re ready to dig into the specifics of the law a little bit. The good news is that it is relatively simple.

**The first provision is designation**
- When a patient enters a hospital as an inpatient, they or their legal representative are given a chance to name a lay caregiver (to say this is the person – my friend, neighbor, spouse, son, whoever – who is going to be helping me when I get home). The patient is given this chance “as soon as practicable” after admission and before the patient’s discharge or transfer. If the patient is unconscious or incapacitated, then they’re given the chance after gaining consciousness.
- The term "legal representative" is very clearly defined in the bill. It includes only legal guardians, a person who holds a medical power of attorney, or a representative named in a valid advance health care directive. So only the patient or one of these individuals can name a lay caregiver on behalf of the patient.

- There are a couple other definitions that are key here. One is that the designated lay caregiver is someone who is going to help the patient at their "residence" which does NOT include places like nursing facilities, assisted living facilities, group homes, or similar settings. So if the patient is going to be discharged back to one of those facilities, they are not going to designate a lay caregiver. This law is about helping caregivers at home and not in facilities where patients presumably already receive competent care.

- Similarly, the law makes it clear that the designated lay caregiver should not be someone who receives third-party payment. This law is primarily meant to help truly "lay" caregivers, not paid professionals. So a patient may not designate as their lay caregiver someone who, for example, is a paid home care worker from an agency. Now, in some states like Montana, there are Medicaid programs (often called self-directed programs) that allows Medicaid to pay a family member or someone else close to the individual to be their home aide. That is fine, those people can still be designated as a lay caregiver, but your typical paid home health worker cannot be.

- Once a patient does designate a lay caregiver, the hospital's first task is to get the patient's consent to release medical information to that caregiver. This process helps the patient understand that the lay caregiver may be made aware of some medical and health information about the patient as part of this discharge process. We know hospitals already take medical information very seriously based on HIPAA and other laws.
Caregiver Designation (cont.)

- If the patient designates a lay caregiver, the hospital appropriately documents the caregiver’s information (name, address, phone number, and relationship to patient).

- If the patient declines to designate a lay caregiver, or will not consent to the release of medical information, then the hospital documents this choice and is not required to perform the other parts of the law.

- The patient can change the designated lay caregiver at any time.

- If the patient does designate a lay caregiver, then the hospital appropriately documents the caregiver’s information – their name, address, phone number, and relationship to the patient. The hospital can document this in the patient’s medical record, or elsewhere -- the law doesn’t specify.

- The patient can choose NOT to designate a caregiver; that’s fine, the hospital just needs to give them the opportunity. If the patient declines to designate a lay caregiver or won’t consent to the release of medical information, then the hospital documents that choice. Because the patient has not designated a lay caregiver, the hospital can’t perform the other parts of the law, so they’re effectively off the hook for those.

- The patient can also change their designation of lay caregiver while they’re in the hospital if circumstances change (for example, the caregiver is out of town or something).
Caregiver Notification

• The hospital notifies the designated lay caregiver of the patient's impending discharge or transfer to another facility as soon as practicable.

• If the hospital is unable to contact the lay caregiver, the lack of contact will not interfere with the medical care or appropriate discharge of the patient.

The second major provision is notification

• This one is pretty simple. The hospital notifies the lay caregiver as soon as practicable of the patient's impending discharge home or transfer to another facility. The law says that this may be done after the physician issues a discharge order and prior to the patient's actual discharge or transfer.

• If the hospital can't get ahold of the caregiver, they simply document that. The lack of contact doesn't mean the hospital can't go ahead with their plan to discharge the patient, but the hospitals need to make the attempt. Again, this is something we worked on with MHA to make sure these requirements were workable from the hospital perspective.
Caregiver Instruction

- As soon as practicable before the patient’s discharge, the hospital:
  - Consults with the lay caregiver and the patient
  - Issues a discharge plan describing the aftercare needs of the patient, taking into account the capabilities and limitations of the caregiver, and including contact information for relevant follow-up care and resources
  - Provides the lay caregiver with an opportunity for instruction in the aftercare tasks described in the discharge plan, provided in non-technical language, in a culturally competent manner, and with a chance for the caregiver to ask questions. Instruction may be conducted in person, by telephone, or by video technology at the discretion of the lay caregiver.

Finally, and maybe most importantly, the third provision is instruction.
- Prior to discharge, the hospital consults with the lay caregiver about the patient’s aftercare needs and issues a discharge plan that describes those aftercare needs, along with contact information for any follow up care or resources that are necessary to successfully carry out the discharge plan. The “aftercare” involved here are the types of things that the lay caregiver is going to be expected to provide to the patient at the patient’s residence. It does not include the types of medical or nursing tasks that require a licensed professional.
- Part of this includes giving the lay caregiver an opportunity to receive instruction and ask questions about the aftercare tasks. This instruction can be done in person, by telephone, or by video technology at the discretion of the caregiver.
- Now, this is not a long law, it’s only a few pages long, so what I’ve gone over really is the meat of the law. It puts in place the very basic requirements and then leaves a lot to the hospitals to determine how to fit those requirements into their procedures.
- There are certain protections built into the law, both for caregivers and for hospitals that you should be aware of.

- First for the caregivers, patients are not required to designate a lay caregiver, and even if they do, those lay caregivers are not required to perform aftercare tasks. This law is about providing instruction and support to those caregivers who are voluntarily helping their loved ones. Being designated as a lay caregiver doesn’t mean that person is conscripted into providing aftercare forever more. We don’t anticipate this being a huge problem as the majority of the time the patient and the caregiver will already have a close relationship and an understanding of the kind of help that is needed and that the caregiver can provide.

- Also, being designated as a lay caregiver does not give that individual any authority to make healthcare decisions on behalf of the patient. This law does not impact healthcare decisions at all. If someone has a valid healthcare directive before entering the hospital, that is still the operative document and designation as a lay caregiver does not change that. Of course, we recognize that sometimes the person designated as the lay caregiver may also be the same person who holds a medical power of attorney (a spouse, for example), but those are totally separate designations as far as this law is concerned.
- Similarly there are protections for hospitals built into the law.

- First, nothing in the Caregiver Act will affect the medical care or the appropriate discharge or transfer of a patient. So, for example, if the hospital is unable to contact the lay caregiver, the hospital can proceed with discharge as it would normally. This law is designed to build off of existing procedures and not add major new obstacles for hospitals.

- Also, regarding liability, the Caregiver Act does not create any new right of action against a hospital or its personnel. So patients or their caregivers cannot sue a hospital under the Caregiver Act, but of course they can still bring a civil suit against a hospital under a negligence claim or whatever other claims are currently available to patients (nothing can really change that). The point is that the Caregiver Act does not fundamentally change the existing liability landscape for hospitals. In fact, there is a provision in the law that states that hospitals and their personnel will not be liable for the services rendered or not rendered by a lay caregiver if the hospital has complied with the law and acted reasonably and in good faith. Sadly, even after receiving instruction, caregivers may still make mistakes. Hospitals won't be liable for those if they've complied with this law.
Implementation and Education

- The Montana Caregiver Act takes effect October 1, 2017.

- Hospitals, AARP Montana, and other groups are encouraged to work together to educate the public and ensure an effective implementation.

- As has been mentioned, the Montana Caregiver Act takes effect October 1.
- In order for implementation to be effective, stakeholders really need to work together. This includes operationalizing the law, figuring out how it will work on the ground in hospitals (and Dick Brown is going to talk a little bit more about that), but also educating patients and the public.
- A number of hospital systems across the country where similar laws have been enacted have really taken up the task of educating the public. You see here on the left is a brochure from Mountain View hospital in Nevada. This is something they did completely on their own, designing it, and including it in admission materials for patients. We would love to see hospitals in Montana do the same, and we’re happy to provide you with examples or work with you on content if it would be helpful. AARP has also been working on educating the public on our own and will continue to do so. We’ve done press releases, op-eds in newspapers about this, and we even printed up some wallet cards like you see on the right to hand out to the public that briefly explains the law and what patients and caregivers can expect now when they enter the hospital.
- I just wanted to reiterate how grateful we’ve been for the collaboration with MHA on this effort. This truly is a great opportunity to make sure Montana caregivers are getting the support they need and are helping their loved ones transition back home safely after a hospital stay. We look forward to continuing to work with you on this and other efforts.
Caregiver Decision Tree – This slide provides a diagram regarding a patient or legal representative’s decision to designate a Caregiver. It is a visual explanation of the points discussed on the previous few slides.

If a patient does not designate a Caregiver you simply document the decision and no further action on this issue is necessary. If a Caregiver is designated then you have several steps along the way to assure the Caregiver is kept informed of the patient’s status and ultimately is prepared to care for the patient when they return home. At any time along the path a Caregiver designation can be ended by the patient or the Caregiver. However, in those cases an alternate Caregiver may be designated.

If a Caregiver is in place when the patient is to be discharged, you need to:
Provide & document necessary lay Caregiver’s training/education in a culturally and linguistically appropriate manner for a compliant discharge plan. And you need to document instructions, date and time, resources, providers, resource person at hospital to answer questions, relationship to patient, name telephone, and address.
**Hospital Implementation**

- Assess existing discharge planning policies to ensure they meet the Conditions of Participation (§482.43)
- If these items do not currently exist in written policies and procedures, add or incorporate the following for all inpatients:
  - Inquiry process regarding lay caregiver designation (and what to do if patient declines)
  - Obtaining written consent to release information to caregiver
  - Location designation for documentation of caregiver information and instructions (name, relationship to patient, telephone number and address)
  - Notification (& documentation) of lay caregiver for patient’s impending discharge or transfer
  - Instruction of aftercare tasks to lay caregiver—content and methods used

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Hospital Implementation – a quick review of your responsibilities

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  1) An inquiry process regarding lay caregiver designation (and what to do if patient declines)
  2) Obtaining written consent to release information to caregiver
  3) Location designation for documentation of caregiver information and instructions (name, relationship to patient, telephone number and address)
  4) Notification (& documentation) of lay caregiver for patient’s impending discharge or transfer
  5) Instruction of aftercare tasks to lay caregiver—content and methods used
Additional Key Points

- ‘Aftercare’ means assistance with ADLs, IADLs, medical/nursing tasks that do not need a professional
  - Take into account capabilities of caregiver
  - Include contact info for follow-up care & resources
- If patient is incapacitated upon admission, may ask legal representative to designate a lay caregiver
- Patient or legal representative may change caregiver at any time; document this if it occurs
- The designated caregiver is not obligated to perform the aftercare tasks

Finally, we did have a question regarding whether or not this legislation included Swing Bed patients and based on our initial research it does not.
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