

Plain Talk about Providing Health Care to Plain Communities

I. Introduction

As their numbers grow in Wisconsin signs of Plain Amish and Mennonite communities are becoming more familiar. Horse-drawn buggies, woodworking shops, greenhouses, bakeries, bulk food stores, along with other Amish and Mennonite businesses are more common. Because of this increasing familiarity, we may feel we know or understand this culture. However, familiarity must not be confused with understanding, especially as we strive to provide effective and economical health care to this unique cultural group in our midst. Understanding the history of the Plain movement, the organization of contemporary communities, and the variations among the different groups that have settled in Wisconsin can give health care providers a foundation for the lifelong process of learning to provide respectful and appropriate health care to this population.

The Amish, Old Order Mennonites, and German Baptists are among the groups in Wisconsin that identify as Plain communities. These groups share a history that can be traced to the Anabaptist movement, which began in 1525 in Switzerland at the time of the Protestant Reformation. The Mennonites were established in the mid 1500's. The Amish separated from the Mennonites in 1693 following their leader Jacob Ammann. Both of these groups experienced religious persecution in Europe and migrated to North America beginning in the first half the eighteenth century. Since that time many offshoots of these groups have formed usually because of differences of opinion over how to apply their shared faith to everyday life. Members of these groups have continued to dress simply with subtle, but significant differences in clothing style between the groups such as sleeve length, clothing fasteners, and color of fabric. In general, Mennonites represent a diverse group and most do not wear plain dress. The Old Order Mennonite communities wear plain dress. For the purposes of this guide, members of Amish, Old Order Mennonite, and other Plain communities who wear plain dress and live according to their Christian faith will collectively be referred to as Plain people.

Over 300,000 Amish and 30,000 Old Order Mennonites live in North America. Since 2000, Wisconsin has had the largest number of new Amish and Mennonite settlements in North America because of a surge of migrations from other states. Plain people make up Wisconsin's fastest growing minority. Nearly half of Wisconsin's counties include Amish or Old Order Mennonite communities. An approximate estimate of the current Plain population in Wisconsin is 20,000 individuals.¹

The Amish drive horse-drawn buggies and do not have a telephone or electricity in their homes. Old Order Mennonite communities allow electricity and telephones in the home, but several groups in Wisconsin drive horse-drawn buggies. Plain communities are organized around church districts and governed by a set of rules specific to that church. As a result of this structure, there is much diversity among the different church districts regarding what technologies are allowed, how much interaction with the "English" (the term used by Plain communities to describe everyone outside their communities) is acceptable, and many other aspects of daily life.

¹ This estimate is based on information from a number of sources listed in the references and also includes anecdotal

II. Guidelines and Considerations for Providing Health Care to Plain Communities

Cultural barriers to health care

Western medicine is often not their first choice for health care

The Plain culture is based on strict adherence to Christian principles. They believe God is the giver of life, health, and healing. Plain people believe God will act through their prayers to work healing, but Plain people should not be confused with other religious minority groups, such as Christian Scientists and Jehovah's Witnesses, who set specific limits on certain medical practices. Very few Plain communities rule out any drugs, surgeries, or treatment options categorically based on religious grounds. Health care needs of Plain communities are similar to the general population and include maternal & child health, treatment of infectious and chronic diseases, and injuries (such as farm and buggy accidents). In addition, numerous genetic and metabolic conditions, found in the general population, can occur at a higher frequency in the Plain communities and thus require care and treatment by health care providers with subspecialty training.

Complementary, homeopathic, and alternative medicine regimens are commonly used

Home remedies, herbal treatments, and supplements may be used preventively, for treatment of symptoms, and are often preferred over standard Western medicine treatments. Some Plain people are concerned that they will receive unwanted medical interventions, have large medical bills for unnecessary tests, care, and procedures, and lose control of medical decision-making when going to the doctor or hospital. Because of this, many Plain people will not seek medical care until absolutely necessary or until an illness is quite advanced. When taking a history, specifically ask about supplements, herbals, homeopathic medicines, and cleanses to comprehensively assess drug interactions or identify contraindications, such as pregnancy.

Midwifery care and out-of-hospital births are preferred

Practices regarding prenatal, postpartum, and birth care vary a great deal among Plain communities. Most Plain families prefer to deliver their babies in out-of-hospital settings. Often these births are attended by a midwife, some of whom are licensed providers and some of whom are members of the Plain community. Most Old Order Mennonite families start prenatal care around 3 months of gestation and continue routine prenatal care during the pregnancy. Amish families often choose limited prenatal care beginning later in pregnancy. A few Amish families choose to have only the husband or family member help with the delivery and may have little or no prenatal care. Midwives frequently become trusted advisors to Plain families. They can serve as a resource to other health care professionals regarding Plain culture and health practices. Plain families of ten or more children are not unusual. Medical forms of birth control are not typically practiced. Herbal teas are used even with babies, therefore education regarding optimal breastfeeding practices is helpful. A guide to perinatal topics is available for use with families entitled: "*Plain Talk About Babies*" (see Additional References).

Preventative health care, screenings, and immunizations for children and adults are not routine

Many Old Order Mennonite families have well-baby visits and accept immunizations for their children. Rarely, Amish families have routine well-baby visits and many opt out of immunizations. Newborn blood, hearing, and heart screening must be actively pursued in all Plain communities because of the increased incidence of the genetic/metabolic diseases in this population. It is not uncommon for an Amish person to have reached adulthood without ever having received care in a typical health care setting. It is important to check with first time patients to make sure they are familiar with routine health care procedures, such as blood pressure checks and lab draws.

Air transport is prohibited by some Plain communities

For some communities transport by air is against the rules of the community. Ask families before arranging helicopter transport and consider ground transport if at all possible.

Access to medical care

Plain people do not have health insurance

All efforts to reduce health care costs benefit Plain families and their community. As is true for health care in general, health care providers should carefully consider the necessity of diagnostic tests and the efficacy of treatments. The cost of health care and the need to be judicious in ordering tests and treatments is further amplified with care of members from Plain communities. Most Plain people do not have health insurance and are categorized as self-pay. Often during the care of members from Plain communities, health care providers will be asked to justify the need for recommended tests and treatments as well as provide the associated costs that will be billed to the family. Providing detailed costs may not be feasible for most health care providers. Several medical facilities in Wisconsin work with Plain communities to develop payment rates and Memorandums of Understanding; it is recommended that providers understand the agreements that have been negotiated between their facility and Wisconsin Plain communities. Additionally, early involvement of representatives from the billing department who have experience working with Plain communities and an understanding of the Plain culture is advised. Payments for medical care are made with cash or check. Most members of Plain communities sign IRS Form 4029 when they join the church. This exempts them from paying Social Security and Medicare taxes and waives their right to receive these benefits. Because Plain people do not pay into this system, they choose not to accept benefits such as Medicaid and other federally-funded health care programs (Plain communities are exempt from Affordable Care Act requirements). Plain people are not exempt from paying all other state and federal taxes. Some families with special needs children may accept Medicaid only for that child or other state-run services such as WIC.

Members of Plain communities may participate in a voluntary donation plan that is administered by the church clergy and may be accessed for medical expenses. In some church districts, a general appeal for funds may be made to cover community health care costs. The decision to use the funds for a specific purpose rests with the church ministry. Therefore, a family might not make an immediate decision regarding a medical test or procedure as they would first need to meet with the church leaders regarding the urgency, necessity, and cost of the

medical recommendations. Cost should also be considered when making transport decisions. Requests for transport by private vehicle should be considered if it is at all feasible.

Families will often seek medical care at health care facilities in other states. This occurs because of transparency about medical costs and reduced costs compared to services available locally. This can also occur because of the type of services offered. For example, Plain Community members will travel together in vans to seek diet therapies or chiropractic care. Seeking medical care in Canada and Mexico to reduce costs or receive alternative therapies is common. This can pose additional challenges such as prescriptions written in Spanish and difficulty in obtaining complete medical records.

Most Plain people in Wisconsin travel by horse and buggy

Many Plain families came to Wisconsin because of the relative abundance of affordable land in rural areas. This distance from medical centers, especially tertiary care centers, makes finding medical care within reach by horse and buggy challenging or non-existent. Most Plain families will arrange transportation with English neighbors or a transportation service, but this may be difficult and expensive. Whenever possible, efforts should be made to work with local providers (primary care physicians, public health nurses, or licensed midwives) to coordinate care and reduce needed travel.

Many homes do not have electricity or telephones

Due to the lack of electricity some medical equipment such as phototherapy lights or oxygen condensers, may not be acceptable or practical options in home care settings. Communication between clinic visits is frequently accomplished by use of a phone in the barn or a community phone. Timing of these calls may be planned in advance for the convenience of all involved. Written communications may also be needed.

III. General Guidelines When Caring for a Member of a Plain Community

Most Plain people speak Pennsylvania Dutch (a language related to German) as their first and preferred language

Typically, English is not spoken by children until they enter school at age 6 years. It is important to recognize that in stressful situations some Plain people may have difficulty expressing themselves in English and may appreciate an interpreter. Allow discussion among family members in their native language. It shows great sensitivity to leave the room to allow families to communicate amongst themselves. The style of communication in Plain communities is often slower paced than many health care providers are accustomed and includes thoughtful listening accompanied with slow and considered responses. Medical terminology may be unfamiliar as it is not routinely encountered in the daily lives of most Plain people. Plain people may be reluctant to let a health care provider know that they have not understood explanations or instructions.

Most Plain adults have received an excellent education through the eighth grade

Most adults in Plain communities have completed an eighth grade education in their independent schools. New schools are formed when a Plain congregation is large enough to support their own first-through-eighth-grade school. Children receive an excellent education that serves them very well in their homes, their communities, and their employment. This educational experience does not include technical medical information or complex scientific concepts. To help a family with medical decisions, explain medical concepts simply but accurately and completely, remembering that English is a second language. Truth is valued. Avoid being inaccurate in an attempt to be simplistic. Slow the pace down and allow time for questions.

Most electronic media are not allowed

Most Plain communities do not allow electronic media such as television, video games, computers, and radios. Do not offer these items to children.

Cultural dietary restrictions are not typical

In general, there are no specific cultural dietary restrictions or needs for Plain people. Individuals with metabolic disorders are on specialized diets throughout their lifetime. As with any group, the diet among different Plain communities and within individual families is quite varied. The typical Plain diet is a turn-of-the-century farm diet with much of the food being grown and preserved by the family. In the 1980s, a survey of Amish in Ohio indicated they practiced healthier nutritional behaviors than typical Americans. In recent years, eating patterns in some communities have changed to include more highly-refined carbohydrates, fats, and processed foods with low nutrient density.² As a result, Plain diets may be low in high-quality sources of protein and fresh foods, especially during the winter months. Silent prayer before and/or after each meal is important to Plain people. Making sure that families have time and privacy to observe this ritual is appreciated.

Modesty is part of the Plain culture

Allow for privacy when undressing and dressing. During a physical exam uncover only what is necessary. For example, covering the feet and legs of a mother while exposing the abdomen allow for a prenatal exam that is much more comfortable. For Plain women, it is important to have a head covering at all times. Some Plain women may prefer a scarf when they are in bed, but may want their prayer cap when they have company. Note that a “prayer cap” is not the same thing as a “bonnet,” which is a larger head covering worn by many Plain women over their prayer cap when traveling. It also honors their cultural sensibilities for health care providers to dress modestly when caring for Plain people. When working with these families, female health care providers should consider wearing clothing that covers knees and elbows and has a modest neckline. Those with long hair may choose to wear their hair up or braided as a sign of respect. In addition, Plain people’s sense of modesty may extend to the topics they are willing to discuss. Plain people may refrain from or be reluctant to discuss intimate health topics relating to birth control, mental health, or sexual disorders.

² Observational reports from health care providers working in Plain communities

Pregnancy and childbirth are a private matter, typically discussed only between husband and wife

Children are considered a gift from God and large families are the norm. It is customary in Amish communities that no mention of a pregnancy is made in the immediate or extended family. In Old Order Mennonite communities, most couples talk with immediate family members and sometimes close friends about a pregnancy, but not with children under 14 years of age. If a pregnant woman is seen by a health care professional in the presence of her other children, do not speak of the pregnancy or refer to the unborn fetus. These topics are considered a private and sacred matter between husband and wife. Note also that Plain people do not speak with the same degree of certainty about impending births that English people do. In general, it is regarded as inappropriate to automatically assume that a child will be born healthy (or not). That is why Plain families never have baby showers or accept baby gifts before the birth; that would be viewed as tempting God.

A number of serious genetic disorders occur at higher frequency in Plain communities

The increasing population size of Plain communities is a result of large family size and improved health care, not recruitment of new members. A number of serious genetic disorders, present in the general population, are found in greater frequency in Plain communities as a result of founder effects and a genetically-closed community. There is awareness in Plain communities of the need to avoid marriage between first or second cousins to prevent these genetic conditions, but reinforcement of this guideline by health care providers is warranted. Many of these diseases are part of newborn screening (NBS) and provide a strong rationale for promotion of newborn blood, hearing, and heart screening for Plain communities. Examples of serious genetic diseases present at higher frequency in Plain communities and screened for with NBS include severe combined immunodeficiency (SCID), maple syrup urine disease (MSUD), and glutaric aciduria type 1 (GA1). Health care providers who work with Plain communities should be familiar with the genetic disorders (see Resources) common to the communities. Some disorders can present with symptoms similar to common illnesses, but require highly specialized care. Therefore, health care providers in the field are best served by developing strong working relationships with subspecialists at tertiary care centers.

Look to the husband, as head of the family, to make the final decisions regarding medical treatments

Plain families adhere to the Biblical directive for husbands and fathers to be the head of their household. Men accept this responsibility with care and sincerity. Health care providers should explain medical results, findings, treatment plans, and explanations to all adults in the family, but look to the husband to make a final decision. Most husbands deeply value the opinions and wishes of their wives and will consult with them when making important decisions. A family might defer making a decision regarding a significant and expensive treatment until a bishop or minister of their congregation can be consulted. Even if the timing of a treatment is urgent, it is typical for a family to seek the counsel of church leaders before making a final decision.

Considerations regarding medical decision-making for children

Plain families and health care providers have faced difficult situations when a medical provider believed an ill child needed care or interventions and the parents were reluctant or did not agree. In rare cases, hospitals or doctors have gone to the courts to gain medical custody of children in order to initiate or continue care against the parent's wishes. As expected, these events often have a negative impact on the relationship between the family and the medical facility. Additionally, because of the close-knit nature of this culture, these events also lead to erosion of a trusting relationship between the medical facility, its health care providers, and the many families within the Plain communities. The erosion of this trust can be difficult to repair and may never be re-established.

Health care providers are required to act in the best interest of the child under their care and are mandated to report medical neglect to the appropriate authorities (per Wisconsin State Statute 48.981). The determination of medical neglect and establishment of imminent danger for the child cannot be outlined by a clearly defined algorithm. Ideally, decisions about what is truly in the best interest of the child can be made within the context and belief system of the child's culture. Plain families deeply love their children and with few exceptions provide remarkable care, and they want their children to live and thrive. In the case of a critically ill child who needs painful and difficult procedures that have a limited hope for success, many Plain families feel that the kindest and most loving thing that they can do is accept God's will for this child and release that child from earthly suffering into God's hands. This can be difficult for health care providers when there is a possibility, even if it is slim, that the child could recover with treatment. In these situations, the health care providers may view the risks and benefits differently than the family and community members. Often these difficult decisions need to be made in emergency situations when there is a great deal of stress and anxiety. While time is often of the essence in these situations, the following is a list of suggested services and guidance that should be offered and available to the family and health care providers:

1. A quiet and calm atmosphere of respect and shared decision-making.
2. Clear and honest explanations of the child's current condition and chances for recovery.
3. The opportunity to contact family and clergy and involve them in decision-making.
4. A willingness to provide only the most necessary treatment while awaiting the arrival of family members or clergy.
5. Private opportunities for the family to pray and converse in Pennsylvania Dutch at the bedside.
6. Involvement of health care providers who understand and respect the faith and cultural values of Plain families and, most importantly, have established a trusted relationship with the community. Inclusion of social work and ethics committees to provide additional guidance for the family and health care providers is also recommended.

7. Inclusion of a staff person, preferably one who speaks Pennsylvania Dutch, to serve as an advocate and cultural liaison for Plain families.

Plain people value life, yet are accepting of pain, illness, disability and death as a part of life

Mainstream American culture often seems conflicted in its efforts to preserve and sustain life at all costs, while needing to relieve pain and suffering through assisted suicide or abortion. Neither extreme will be seen in the Plain community. Children and adults with disabilities are cared for with great love and acceptance and are seen as valued members of the community. Plain people often decide to forgo extreme measures to save a life as they accept death as God's will.

In spite of some of the unique challenges in health care delivery when serving the Plain communities, health care professionals who have worked with this culture for many years would not have it any other way. Like all cultures, there are many differences between Plain communities and the individuals within those communities. It is hoped that this guide will increase the understanding of health care providers who have the opportunity to provide care to members of Plain communities.

IV. Resources

Contacts for more information on cultural aspects of providing care to Plain families:

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For information on genetic disorders in Plain Communities:

Amish, Mennonite, and Hutterite Genetic Disorder Database
www.biochemgenetics.ca/plainpeople/

Windows of Hope Project-Understanding Inherited Conditions
<http://www.wohproject.org/>

For referral/consultation on genetic disorders in Plain communities:

Waisman Center Genetics Clinic
1500 Highland Ave. Rm 359
Madison, WI 53705
Phone number: (608) 263-5993 or (608) 890-2631
Business Hours: Monday through Friday, 8:30am-5:00pm
After Hours (urgent or emergency calls): (608) 262-2122 ask for on-call metabolic
doctor

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608-263-2652

La Farge VMH Medical Home for Special Children and Adults
111 W Snow Street
La Farge, WI 54639
608-625-2494

Clinic for Special Children
535 Bunker Hill Road
PO Box 128
Strasburg, PA 17579
717-687-9407
<https://clinicforspecialchildren.org>

DDC Clinic-Center for Special Needs Children
14567 Madison Road
Middlefield, Ohio 44062
440-632-1668
<http://www.ddcclinic.org>

V. Additional References

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