

CONNECTIONS

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Introducing the Alzheimer Society of Niagara's Advisory Committee



The advisory group is composed of six individuals who are living with dementia. The advisory committee was established to ensure the voice of those living with dementia was heard and valued in the day to day workings of the Alzheimer Society. When making choices that will impact those living with dementia, it is critical to recognize that without their voices being heard in the process, the society would be making choice FOR rather than WITH these individuals. The group is often asked to give their input on upcoming programs and education packages; as well as having opportunities to provide their experiences to the Alzheimer Society of Canada and other organizations seeking insight into the face of dementia. The help the Advisory Committee provides to our local Society is incredibly valuable and so we wanted to share with our members why these resilient, amazing six individuals decided to be a part of our Advisory Committee.

“Coming here is the best medicine.” – Maisie Jackson

Maisie:

I enjoy coming to the committee to enjoy my time with peers. It helps me to recognize what [the government] has been working on in terms of helping those with dementia and then be able to share with my family what is going on. I am still able to have a voice and share my thoughts. Also, as a group, we help each other feel better about the current situation.

Irma:

Afterwards I can share with my son what we talked about during the meeting and make him aware of some of the struggles and topics that we discuss. It helps us learn and educate and at the same time how to help the community. We are thankful for the society because we know that there is help from people who care about us.

Bev:

The advisory committee gives us a chance to make a difference for dementia and our future. We have a good group and everyone has a different opinion. I think that it is good always going home learning something.

Harry:

I love being a part of the advisory group. We are all of one accord, this group we lift each other up. Look at what we can contribute. It is important to hear everyone's input.



Bea:

When we come here we can discuss how we feel, how changes need to occur in the [Alzheimer Society's] programing and educational handouts. We invite the people to our group who work on these projects to give them ideas because we can still be a part of the change. We don't always need to take help, but we can also give back. [With dementia], we can still smash barriers and discuss ideas on how to do so. It gives you an empowered feeling that when we go home to our communities we don't always have. These days, we think better together – together we can create a teepee of knowledge that I think can help everyone. Anyone can talk about how things have to change, but to be so privileged that we can be a part of that change is indescribable.

Earl:

I want to let people know that Alzheimer's is not the worst thing that could ever be. I want to enlighten people about what Alzheimer's is all about. I have good days and bad days. When they come, they pass and I know that I just cannot give up. I have no desire at all to call it quits because I have too much living to do which is worth too much to me. I stay strong because we're doing ok! And it's funny 'they' are listening to us even though we are the ones who can get confused; that says something.



Brain Wave Café

The **Brain Wave Café** provides an opportunity for individuals concerned about cognitive change and dementia to learn about brain health and dementia, to ask questions, and to become familiar with community resources and supports. These cafés offer an informal place for people to meet up on a regular basis for a coffee, get information, share experiences and participate in 'healthy brain' activities within their local communities. Individuals living with cognitive change or dementia, care partners, family and friends are all welcome! If you would like to learn more about the **Brain Wave Café**, please call the Alzheimer Society of Niagara Region and ask to speak to the First Link Coordinator for further information: **905-687-3914**.

Centre de Santé Communautaire
(**Francophone** Brain Wave Café)
810 rue East Main, Welland
1st & 3rd Tuesday of the Month
1:30 – 3:00 pm

Goodwill Community Centre
(**Welland** Brain Wave Café)
1 Churchill Ave. Welland
2nd & 4th Tuesday of the Month
1:30 – 3:00 pm

Mountainview Christian Reformed Church
(**Grimsby** Brain Wave Café)
290 Main Street East, Grimsby
1st & 3rd Thursday of the Month
1:30 - 3:00 pm

St. John Anglican Church
(**Niagara Falls** Brain Wave Café)
3428 Portage Rd., Niagara Falls
1st & 3rd Wednesday of the Month
1:30 - 3:00 pm

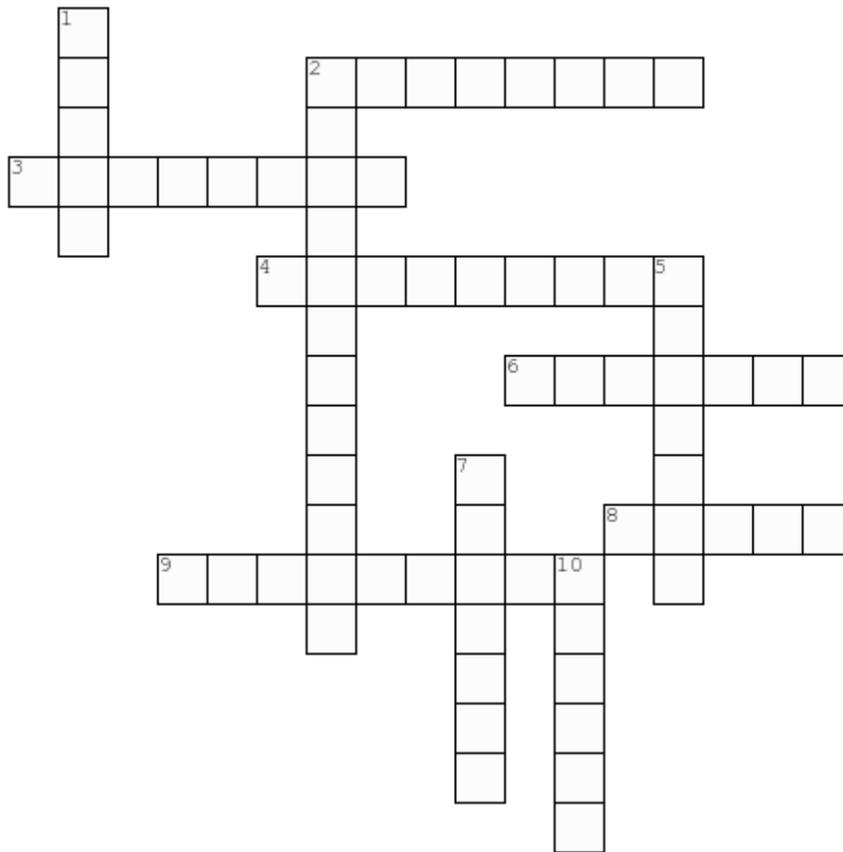
Royal Canadian Legion
(**St. Catharines** Brain Wave Café)
2 Chestnut St., St. Catharines
2nd & 4th Tuesday of the Month
1:30 – 3:00 pm

Thorold Public Library
(**Thorold** Brain Wave Café)
14 Ormond St. N, Thorold
1st & 3rd Wednesday of the Month
1:30 - 3:00 pm

BRAIN GAMES

Riddle of the Month:
“What bites but has
no teeth?”

WINTER WONDERLAND



Across

2. A celebration that involves lighting a menorah
3. Something that looks very pretty around the Christmas tree
4. Sometimes, people come to sing _____ carols!
6. A popular Christmas character with a red nose
8. Someone big and jolly
9. How to get a Christmas smooch

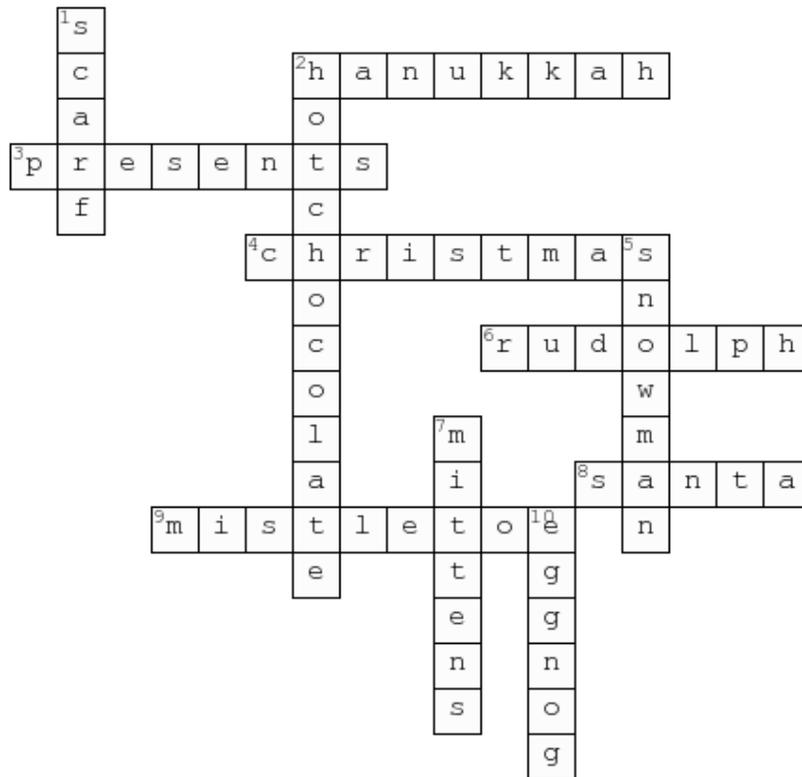
Down

1. Warm and fuzzy around your neck
2. Yummy, warm drink to have while doing winter activities
5. Little kids like to build these when the snow comes
7. How to protect your hands from the cold
10. A winter time drink that is often only served for adults

BRAIN GAMES

Riddle Answer:
"Frost"

WINTER WONDERLAND

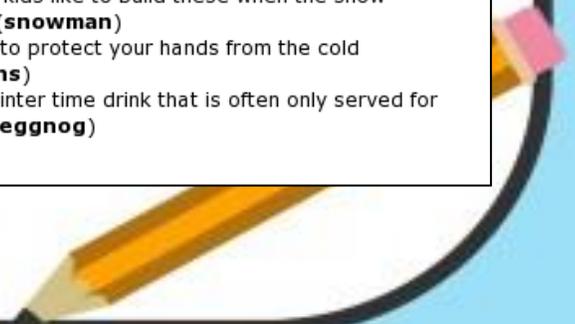


Across

2. A celebration that involves lighting a menorah (**hanukkah**)
3. Something that looks very pretty around the Christmas tree (**presents**)
4. Sometimes, people come to sing _____ carols! (**christmas**)
6. A popular Christmas character with a red nose (**rudolph**)
8. Someone big and jolly (**santa**)
9. How to get a Christmas smooch (**mistletoe**)

Down

1. Warm and fuzzy around your neck (**scarf**)
2. Yummy, warm drink to have while doing winter activities (**hotchocolate**)
5. Little kids like to build these when the snow comes (**snowman**)
7. How to protect your hands from the cold (**mittens**)
10. A winter time drink that is often only served for adults (**eggnog**)



Interview of the Advisory Committee

The topic of community inclusion has come up in discussion frequently over my time at the Alzheimer Society. When I asked the Advisory committee what topic they wanted their interview to be on, unsurprisingly community inclusion was the topic that was decided on. Community inclusion encompasses what it means for someone with dementia to continue to integrate themselves into the community in a productive, satisfying way. Often those with dementia face social obstacles due to underlying negative stigma against dementia, but also practical obstacles such as limited transportation and mobility to get to community organizations. The group wanted to share what community inclusion would mean to them and some other thoughts on the matter.



What Does 'Community Inclusion' Mean

When asked what 'Community Inclusion' meant to the committee, they collectively provided several examples of what being included would look like. The group said, there is a sense that you're wanted by the people in the place you are at, no matter where in the community. That there would be opportunities for those with dementia to show skills that they have because having dementia does not mean that you are suddenly not capable of having skills and talents. An example of how to share their skills is by having opportunities to volunteer in the community with available help/accommodation to do so if necessary. The group often says, "We don't always need to take, we can also give" and volunteer services would be a beneficial way to give back and the advisory group often says this would be a good use of their time.

Community inclusion would mean that you are really wanted since there are times this does not feel like the case for those living with dementia. Bea explained, "It is obvious when someone allows you to be somewhere because of pity rather than a genuine desire to connect".

One of the committee members mentioned Dementia Friendly Communities¹. Dementia friendly communities would mean that there would be staff who were educated on dementia and would know how to best assist those who are in the community and need a second to gather their thoughts. Educated staff would mean that people living with dementia would be able to go into the community with less fear and/or anxiety over doing day-to-day errands or social activities.

A major obstacle that inhibits community inclusion is transportation. Once someone is diagnosed with dementia, it is not uncommon for driver's licenses to be revoked, sometimes, earlier than necessary. For those without a care partner to drive them in and out of the community, transportation becomes a daily and costly complication. Community inclusion for those with dementia would mean that there would be accessible and affordable transportation that could take those living with dementia to social events such as concerts or festivals in the community.



¹ Dementia Friendly Communities are initiatives that countries around the world are integrating. It emphasizes educating communities on dementia to allow everyone to take part in creating accessible communities for those with dementia to live in. For more information, see: <http://www.alzheimer.ca/en/bc/About-dementia/Dementia-friendly%20communities>.

Bea has struggled with transportation since her diagnosis and she explained, “It’s one thing [for those who do not deal with transportation issues] to stand on a stage and say that if you have dementia you need to go out more, you need to socialize – but how do you get there? It’s not that I wouldn’t like to go or don’t know that I should, it is that I can’t.”

Bea shared with the group that the type of dementia that she was diagnosed with has impacted her strength and mobility. With no care partner to help her around, she was stuck inside her apartment where she “stared at four walls for years.” Bea spoke about not being able to go into the mall she lived across the street from. Bea speaks about being blessed to have eventually received an electric wheelchair – although the chair poses its own obstacles with transportation, she feels it has provided her with additional freedom that before she felt was stolen.

The advisory group explains that it’s the little things that we don’t think about, such as educated staff and kindness, that make the largest impacts when considering how to better include those living with dementia in the community.



Personal Stories



I asked the advisory committee times in which they felt included or felt discluded. The advisory group explained that generally in public when store workers are not educated on dementia, they feel excluded. Generally, employees, whether it be at grocery stores or coffee shops, don’t understand why or how to help someone who is confused. A common occurrence is anxiety over paying out at cash register. The group explained that when trying to pay out at the cash, it is easy to lose track of what they are trying to do. Maisie shared that it is at these moments that employees tend to “rush rather than give us a second to gather our thoughts.”

When employees do this, the group explains makes things more confusing. It is times such as these that the group explained they do not feel accepted. “Sometimes the world moves so quickly when you need extra moments and then you get nervous and it all gets worse.” This makes for a negative experience for those with dementia in the community.

Although the group mentioned several other places where they at times feel excluded, such as the doctor’s office, they did not go into much detail because the group wanted to also discuss times that they did feel included. By discussing positive instances, community members can see effective ways at including individuals living with dementia.

One of the group members explained a time when they were in Las Vegas. Earl told us that he was already a little concerned about getting disoriented or lost in the chaos of the Vegas strip. Then, one day in the casino, he turned the wrong way and lost his wife and sister. Earl immediately went to someone who worked there. He explained to the worker that he had Alzheimer’s disease and to get security. The security guard stayed with him until his sister found him. He explained how he felt like this scenario played out well and by being able to share he had Alzheimer’s helped him receive the help he needed.





Another instance was when Bea was able to use her electric wheelchair for the first time one spring. She went to Zehrs and went to the magazine section – Bea is a very talented card maker and so she wanted one of the crafting magazines. Struggling to reach the magazine she wanted from her new chair, she asked the woman beside her for some help. The woman was happy to assist. Bea took this as an opportunity to share with the lady that she had dementia. The woman was initially very shocked by Bea’s assertion because Bea didn’t “seem” like she had dementia. It turned out that the woman had a sister who had just been diagnosed and was feeling grief over prognosis. Bea was able to support the woman and educate her on dementia. Bea explained that she had dementia for about 20 years and it was not the end of the world. Bea shared some personal experiences with the woman and gave some tips on how the lady could effectively be there for her sister. The two of them talked for some time and at the end the woman said, “You were a God sent to me today.” This made Bea feel appreciated because the woman “treated [her] like an equal.” Bea said, “The moment that we are treated as an equal, there is difference between this [moment] and being included because they feel like they have to... it’s not the end of the world when you’re diagnosed.” Earl added, “I think for a second that this is the end of my life, but it is the beginning is so many ways.”

The Advisory Groups Message to the Community

“I’d rather not have dementia, but I’m still able to function. I may forget a little bit, but I can still socialize. We have too much to give and to offer. Having dementia is not the end of the road, it’s just the beginning of a new journey.”



Alzheimer Society of Niagara Region Dementia Advisory Group 2016

Current Research

Music is something that can be appreciated no matter the age, culture or language it is in and it can be appreciated by truly everyone in some way. Music is interesting to scientists because biologically, music does not have a ‘purpose’. There is no reason evolutionarily for music to exist and persist across time. We do not have a ‘music center’ in our brains either like we do with other functions, such as speech or memory. A famous neuroscientist Oliver Sacks explains in his book, *Musicophilia*, “our musical powers... are made possible by using, or recruiting, or co-opting brain systems that have already developed for other purposes”. He explains that music is the “involvement of a dozen scattered networks throughout the brain”.²

Music is interesting to us on an individual level, but due to its ‘lack of biological purpose’, its peculiarity sparks interests in scientists. Even though, scientists are interested in music, no substantial research has been done on how it can benefit people therapeutically. Recently, however, there have been some findings that suggest that music can be used as a therapy to support those with dementia.

The Alzheimer Society of Canada (ASC) explains that music has been found to be a powerful source of joy and comfort for people with dementia. Music is a way that those with dementia can connect and engage with people and memories that might not otherwise be reachable. ASC has a clip online from a documentary “Alive Inside” which emphasizes the impact that music can have on those living with dementia.³ Although there has been research for two decades demonstrating the relationship between music and memory, only recently have researchers been taking these findings more seriously in the context of dementia.

In 2010, a study showed that individuals with Alzheimer’s disease were better able to remember the string of words when the words are sung lyrically than when said aloud otherwise.⁴ This information tells us that the way we encode memory in the brain may be spared for some time during the progression of dementia. A small literature review in 2005 discusses that this could be because music is encoded through the ‘emotion centers’ of the brain rather than our ‘reasoning centers.’ This allows for musical memory to survive much longer than other types of memory.⁵

More research needs to be done to investigate the exact impact of music on helping those with dementia and what exactly it does in the brain. However, for now, many nursing homes are taking up the practice of personalized music therapy which can only be seen to help rather than hurt.



² Sacks, Oliver (2008) *Musicophilia: Tales of music and the brain*. Toronto: Vintage Canada

³ <http://www.cbc.ca/strombo/music-2/video-of-the-day-music-awakens-a-seniors-memories.html>

⁴ Simmons-Stern, N. R., Budson, A. E., & Ally, B. A. (2010). Music as a Memory Enhancer in Patients with Alzheimer’s Disease. *Neuropsychologia*, 48(10), 3164–3167.

⁵ Thaut, M. H. (2005). The future of music in therapy and medicine. *Annals of the New York Academy of Sciences*, 1060(1), 303-308.



Letter from the Editor...

I have had the great pleasure of working with the Alzheimer Society for over a year and a half as both a summer student and now a volunteer. I have worked closely with the Advisory Committee during their meetings to create two Connections newsletters. I have felt very fortunate to meet and connect with the amazing employees and clients of the society. Although I have come to better understand the day-to-day struggles and obstacles that those living with dementia have to face; I have also seen resilience, love, passion, creativity, intelligence, learning and advocacy in ways that I may not have previously believed was possible.

I am personally inspired to do and be better by the individuals I meet and have grown to feel passionate about ensuring that the community comes to better understand what having dementia is really like. The stigma associated with the word dementia has negative and untrue connotations and I am glad that through the creation of these newsletters I am able to be a part of changing how people think of dementia.

I hope to inspire those in the community to see dementia differently, to see dementia how the Advisory Committee does – as not an end, but a new beginning. People have so much to give to one another and this is not something that changes with a diagnosis and I hope that some of what you read in this newsletter demonstrated that fact.

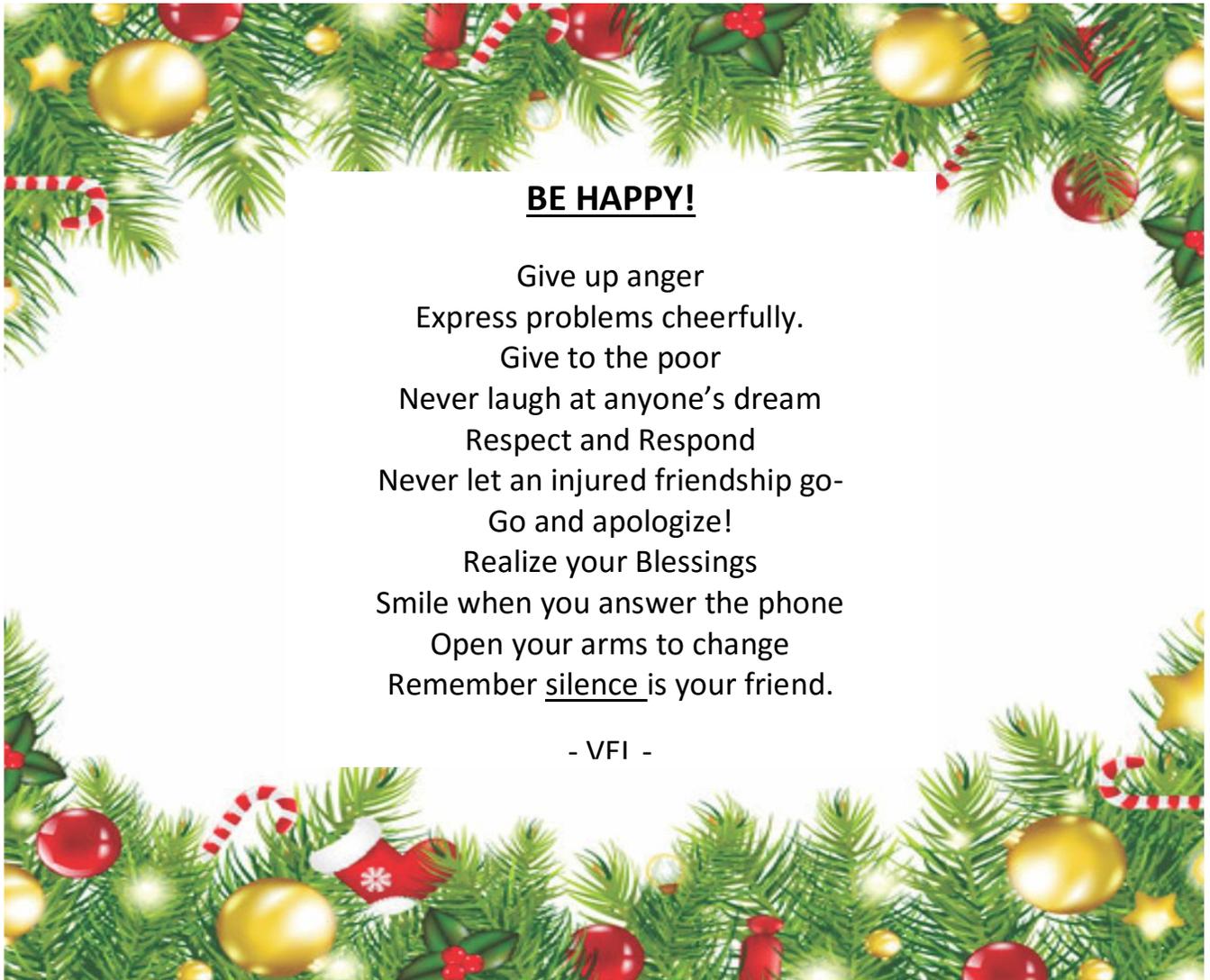
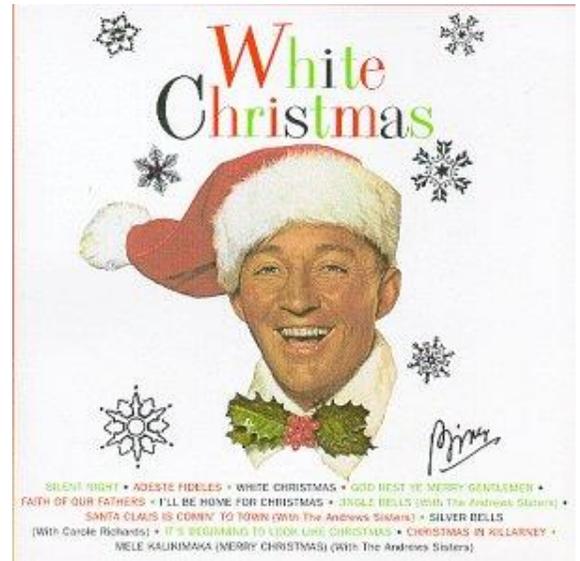
– *Emily Davis*





Remember When...

In 1942, the Song “White Christmas” written by Irving Berlin, and sung by Bing Crosby topped the US Billboard charts for 11 weeks straight. White Christmas returned to the number one spot in 1945 and 1946 becoming the first ever single to have three separate runs at the top of US charts. Since then, the song has been sung by over 100 artists in all different genres of music. White Christmas is ranked the number one Christmas song of all time.



BE HAPPY!

Give up anger
Express problems cheerfully.
Give to the poor
Never laugh at anyone's dream
Respect and Respond
Never let an injured friendship go-
Go and apologize!
Realize your Blessings
Smile when you answer the phone
Open your arms to change
Remember silence is your friend.

- VFI -