ENTRADA
A Patient Experience Organization

# Patient Conversations Analysis Report

## Multiple Myeloma

November 30, 2023

# Definitions

## Surface Behaviors

The predictable events that occur within a disease state as patients move along the journey

## Vulnerable Moments

Points in time when patients feel exposed and need support, and are also open to influence

## Choice Points

Interception points when patients must make a decision that will impact their journey

# What is Multiple Myeloma?

Multiple myeloma is a cancer that forms in a type of white blood cell called a plasma cell. Healthy plasma cells help you fight infections by making antibodies that recognize and attack germs.

In multiple myeloma, cancerous plasma cells accumulate in the bone marrow and crowd out healthy blood cells. Rather than produce helpful antibodies, the cancer cells produce abnormal proteins that can cause complications.

Sometimes myeloma does not cause any symptoms. It may be found when a blood or urine test is done for another condition and a higher than normal level of protein is found. When more advanced, symptoms of myeloma may include bone pain, especially in the back or ribs; bones that break easily; fever for no known reason; frequent infections; bruising or bleeding easily; trouble breathing; weakness of the arms or legs; and feeling very tired.

## Who is affected?

Scientists don’t understand why some people get myeloma and others don’t. Age is the most significant risk factor for developing myeloma. People younger than 45 years old rarely develop the disease. Men are more likely than women to develop myeloma, and myeloma is more than twice as common among Black people as among White people. In rare cases, exposure to X-rays or other kinds of ionizing radiation may be a risk factor for developing myeloma. Being overweight and having obesity are linked with a higher risk of getting multiple myeloma.

Factors that may increase your risk of multiple myeloma include:

- **Increasing age.** Your risk of multiple myeloma increases as you age, with most people diagnosed in their mid-60s.
- **Male sex.** Men are more likely to develop the disease than are women.
- **Black race.** Black people are more likely to develop multiple myeloma than are people of other races.
- **Family history of multiple myeloma.** If a brother, sister or parent has multiple myeloma, you have an increased risk of the disease.
- **Personal history of a monoclonal gammopathy of undetermined significance (MGUS).** Multiple myeloma almost always starts out as MGUS, so having this condition increases your risk.

# Profiles

## BoozyGroggyElfchild

**Age:** 70
**Diagnosis:** Multiple Myeloma
**Treatment:** Neck surgery, chemo (including revlimid), stem-cell transplant
**Relapse:** Yes
**Stem Cell Transplant:** June 29, 2017

## Aggressive-Bus-8055

**Diagnosis:** Multiple Myeloma, AL Amyloidosis
**Treatment:** DVTD treatment (daratumumab, bortezomib, thalidomide, dexamethasone), dialysis
**Stem Cell Transplant:** Stem cell transplant planned
**Other Conditions:** Deposited long chain proteins in kidneys

## Oldey1kanobe

**Treatment:** Darzalex Fastpro
**Blood Work:** Light chains rising

## MyDadAndMyeloma

**Diagnosis:** Multiple Myeloma
**Treatment:** Darzalex, Revlimid, dexamethasone

## RobbedByEndy

**Age:** 59
**Diagnosis:** IgG kappa multiple myeloma
**Treatment:** Darzalex, Revlimid, Velcade, decadron
**Stem Cell Transplant:** 4 months
**Other Conditions:** Sleep apnea, obesity, smoker
**Blood Work:** Kappa Lt chain: 4670.7 mg/L, Lambda Lt chain: 3.6 mg/L, IIg (m protein): 7437 mg/dl, RBC: 2.30 (x 10*6/UL), Hemoglobin: 8.1 g/dl, Platelets: 66 (x 10*3/UL), Creat: 1.28 mg/dl, BUN: 28.5 mg/dl, Calcium: 10.5 mg/dl, Total protein: 11.4 g/dl, Albumin: 3.5 g/dl, Globulin: 7.9 calc

## amy-victor-27

## Adept-Variety2162

## ferndudekween

**Diagnosis:** Stage 1 MM
**Treatment:** Darzalex + Pomalyst + Dexamethasone combo OR Lefluomide + Pomalyst + Dexamethasone combo (clinical trial)
**Relapse:** Yes
**Stem Cell Transplant:** Autologous stem cell transplant surgery

# Profile Summary

## Age range
59-70

## Gender
Not specified

## Geographic location
UK, US

## Treatment options mentioned
Darzalex, Revlimid, Velcade, Thalidomide, Dexamethasone, Lefluomide, Pomalyst

## Medical procedures mentioned
Neck surgery, stem-cell transplant, bone marrow biopsy, blood transfusion, dialysis

## Other medical conditions mentioned
AL Amyloidosis, sleep apnea, obesity, preexisting conditions

## Concerns mentioned
Relapse, treatment response, COVID-19 safety precautions

## Supportive measures mentioned
Private messaging, caretaking, singulair for transfusion reactions

## Clinical trial participation mentioned
Lefluomide + Pomalyst + Dexamethasone combo

# General Themes

## Cancer diagnosis and treatment

The prominent theme in these responses is the experience of individuals and their loved ones dealing with multiple myeloma, a type of cancer. The responses provide details about the diagnosis, symptoms, treatment options, and the impact of the disease on the individuals' lives.

## Treatment options

The different treatment options for multiple myeloma are discussed in several responses. These include chemotherapy, stem cell transplant, monoclonal antibody treatments like Darzalex, and various drug combinations. The effectiveness and side effects of these treatments are mentioned, with some individuals experiencing positive outcomes and remission, while others face challenges and relapses.

## Relapse and disease progression

The theme of relapse and disease progression is present in a few responses. Some individuals share their experiences of being initially declared cancer-free but later experiencing a relapse. The emotional impact and the need for further treatment options are discussed.

## Medical procedures and tests

The responses mention various medical procedures and tests associated with multiple myeloma, such as bone marrow biopsies, blood transfusions, blood tests to monitor counts and protein levels, and imaging tests like bone X-rays. These procedures play a crucial role in diagnosis, treatment planning, and monitoring disease progression.

## Side effects and complications

The side effects and complications of multiple myeloma and its treatments are discussed in some responses. These include fatigue, low blood counts, infections, pneumonia, cardiac issues, and respiratory difficulties. The impact of these side effects on the individuals' quality of life and their ability to carry out daily activities is highlighted.

## Support and community

The responses also reflect a sense of support and community among individuals dealing with multiple myeloma. Some offer to chat privately with others who may have questions or need support. The importance of staying strong, looking after oneself, and thinking of others going through similar experiences is emphasized.

## COVID-19 concerns

One response mentions the additional concern of COVID-19 and its potential impact on individuals undergoing treatment for multiple myeloma. The individual expresses worries about the immune evasive strain and discusses the need for precautions to minimize the risk of infection.

## Emotional impact and coping

The emotional impact of multiple myeloma on individuals and their families is evident in some responses. Fear, anxiety, and concern for loved ones are expressed. Individuals share their strategies for coping, such as taking each day as it comes, avoiding excessive research, and seeking support from others in similar situations.

## Treatment decisions and clinical trials

The decision-making process regarding treatment options is discussed in a few responses. Individuals share their experiences and seek advice from others who have undergone specific treatments or participated in clinical trials. The pros and cons of different treatment options are considered, and the importance of discussing these options with healthcare professionals is emphasized.

## Caregiver role

The role of caregivers in supporting and assisting individuals with multiple myeloma is mentioned in one response. The individual expresses concerns about their father's preexisting conditions and the challenges they may face as a primary caretaker. The need for guidance and interpretation of medical information is also highlighted.

# Patient Needs

## Accurate information and understanding

Many individuals are seeking information about their condition, treatment options, and test results. They express a desire to learn and interpret medical terminology and results to better understand their situation.

## Emotional support

Several individuals share their personal experiences and express their fears, concerns, and anxieties. They seek empathy, encouragement, and reassurance from others who have gone through similar experiences.

## Treatment effectiveness

Some individuals discuss their treatment plans and express the need for effective treatments. They share their experiences with different medications and seek advice or feedback from others who have undergone similar treatments.

## Caregiver support

One individual mentions being the primary caretaker for their father and expresses concerns about managing symptoms and providing support during treatment. They seek guidance and information on how to best care for their loved one.

## Safety and precautions

One individual expresses concerns about the ongoing COVID-19 pandemic and its potential impact on their father's treatment. They seek advice on how to navigate safety measures and make informed decisions to protect their loved one's health.

## Clinical trial experiences

One individual shares their relapse and discusses two treatment options, including a clinical trial. They seek insights and experiences from others who have participated in clinical trials to make an informed decision.

# Transcripts

“BoozyGroggyElfchild: I was not my dad's primary companion to doctor's visits, so some of the details may be incorrect or mixed up, but I wanted to share my dad's story. At least an abbreviated version it.

He was first diagnosed in February 2017, at the age of 70. His initial symptoms were neck pain, caused by extensive bone lesions and he needed immediate neck surgery to repair the bone damage. About 6 weeks later, he began chemo. I don’t recall the exact cocktail of drugs, but revlimid was included. After one (!) round of chemo, he was deemed cancer free. His doctor did another round of chemo, just for the heck of it, before his stem-cell transplant on June 29, 2017. He came out in the other side, and was deemed completely cancer-free!

His lambda count was zero for over a year. About 14 months after the transplant, that count began to rise, and in December 2018 it was officially classified as a relapse. I avoided reading a lot of literature after his initial diagnosis and successful treatment, but I did recall reading about the 100% relapse rate, so his relapse didn't come as a shock to me. I read a little bit more to find out what I could expect, and I quickly found out that relapses so soon after transplant usually meant trouble. His counts began to be high enough for treatment in February.

He was again started on revlimid, and a host of other drugs (that I simply couldn't keep track of) until May. His blood counts were taken every three weeks, and not once was any progress evident. He simply wasn't responding. On May 24, he received his first Darzalex treatment, and to say that it wiped him out would be an understatement. He was tired, and it seemed like the fight was wiped from him. He received two further Darzalex treatments, along with a blood transfusion, with still no improvements in any of his counts. His lambda count was over 500.

My mother brought him to the ER on the morning of June 13. His pulse ox was 81, he'd fallen in the middle of the night a few nights prior and was unable to get himself up. My once unstoppable father was so frail. When he arrived at the ER, his body was leaking cardiac enzymes because his heart had to work so hard to counter his low red counts. His platelets were effectively zero. He had pneumonia. He was given platelet infusions, antibiotics, and a full transfusion, but still his blood counts were dire.

After being treated in the cardiac ward for four days, he was moved into palliative care, with the thinking that he'd been wiped out from the Darzelex treatments, and that he might be able to return home for a few comfortable, treatment-free weeks. For three days in palliative care, he got stronger. His lungs were clearing, he was eating more, and he was getting strong enough to speak. After a wonderful night, on Thursday 6/20, surrounded by family he crashed. That was the last night I'd have a conversation with him. Although he wasn't actively getting worse, his red count was still low enough to give him trouble breathing. Friday and Saturday saw him transferred to hospice care, and his breathing became more and more labored. At around 3:00am on Sunday 6/23, he took his last breath.

I'm thankful that we got a few good days with him at the end, and that he died before he was

in any pain. If anyone reading this wants to chat, please fee free to send me a private message.
Love and light to all of you fighting MM and those with loved ones who are.”

## Surface Behaviors:

– Initial symptoms of neck pain
– Immediate neck surgery for bone damage
– Chemotherapy treatment
– Stem-cell transplant
– Rising lambda count indicating relapse
– Restarting treatment with revlimid and other drugs
– Darzalex treatments with no improvement
– Frailty and exhaustion
– Hospitalization and palliative care

## Vulnerable Moments:

– Receiving the initial diagnosis
– Facing the need for immediate surgery
– Dealing with the relapse after successful treatment
– Experiencing lack of response to treatment
– Being hospitalized and experiencing severe health decline
– Transitioning to palliative care
– The crash and decline in health
– Transfer to hospice care
– Final moments and passing

## Choice Points:

– Deciding on the course of treatment after diagnosis
– Choosing to undergo surgery for bone damage
– Deciding to proceed with stem-cell transplant
– Determining the next steps after relapse
– Choosing to try different medications, including Darzalex
– Deciding to seek hospitalization and palliative care
– Considering the option of hospice care
– Deciding on end-of-life care measures
– Making decisions regarding communication and support

“Aggressive-Bus-8055: Hi there, hope you are doing well. I was diagnosed with both Multiple Myeloma and AL Amyloidosis about a year ago.
I have no questions or worries - I just thought I'd write this out incase anyone has any questions.
I'm in the UK and was put on a treatment called DVTD ( daratumumab (Darzalex®) in combination with bortezomib (Velcade®), thalidomide, and dexamethasone) it has worked really well and after 6 months of treatment I'm in remission. I had no issues at all with my treatment. (I was even shown by the hospital how to give myself the bortezomib injections & that enabled me to be able to do that at home & cut down on the hospital visits). At the moment I'm going into hospital every 4 weeks to get a daratumumab injection.
My AL Amyloidosis has deposited the long chain proteins in my kidneys. So I have dialysis 3

times a week for 4.5 hours. There is a specialist unit in London for Amyloidosis that looks after me alongside my local Haematologist. I will be going down there once a year to get tests & have a scan to see how much of the proteins are in my body.
I have also already had my stem cells collected. Apparently once I'm in my second remission I will be getting the stem cell transplant.
For me I've just taken each day as it comes. I don't look at websites as I don't want to be worrying about what ifs.
For everyone that is going through this - stay strong - and look after yourself. I'm thinking of you.
L."

### Surface Behaviors:

– Diagnosis of Multiple Myeloma and AL Amyloidosis
– Treatment with DVTD (daratumumab, bortezomib, thalidomide, and dexamethasone)
– Remission after 6 months of treatment
– Self-administration of bortezomib injections at home
– Hospital visits every 4 weeks for daratumumab injection
– Dialysis 3 times a week for 4.5 hours
– Specialist unit in London for Amyloidosis care
– Yearly tests and scans to monitor protein levels
– Collection of stem cells for future transplant

### Vulnerable Moments:

– Receiving the diagnosis of Multiple Myeloma and AL Amyloidosis
– Undergoing treatment and experiencing potential side effects
– Waiting for results to determine remission status
– Adjusting to self-administration of injections
– Coping with the need for regular dialysis sessions
– Reliance on specialized care from the London unit
– Anxiety and uncertainty during yearly tests and scans
– Preparing for the upcoming stem cell transplant
– Managing emotional and physical well-being throughout the journey

### Choice Points:

– Deciding on the appropriate treatment plan
– Choosing to learn and administer self-injections at home
– Selecting the frequency and timing of hospital visits
– Opting for dialysis as a treatment option for kidney involvement
– Deciding to seek care from the specialist unit in London
– Determining the frequency and extent of follow-up tests and scans
– Electing to undergo stem cell transplant after achieving remission
– Making choices to prioritize self-care and emotional support
– Deciding on the level of engagement with online resources and information

"Oldey1kanobe: My mom is on year 7 of chemo. She has been a champ-fighting so hard. We have run through many drugs. Current is Darzalex Fastpro. Light chains rising. Ugh. Anyone have a pep talk? Getting pretty deep into the bench for drugs."

## Surface Behaviors:

– Progression of disease despite treatment
– Exhaustion from long-term chemotherapy
– Trying different drugs to manage the condition
– Rising light chains
– Seeking support and encouragement
– Feeling discouraged by limited treatment options
– Looking for alternative solutions
– Dealing with the physical and emotional toll of treatment
– Hoping for positive outcomes

## Vulnerable Moments:

– Feeling exposed and vulnerable due to disease progression
– Needing emotional support during a challenging journey
– Open to advice and encouragement from others
– Seeking reassurance and hope in difficult times
– Feeling uncertain about the future
– Experiencing frustration and disappointment with treatment options
– Longing for a breakthrough in treatment
– Struggling with the physical and emotional side effects of chemotherapy
– Desiring a pep talk to boost morale

## Choice Points:

– Deciding whether to continue with the current treatment or explore other options
– Choosing to seek a second opinion from a different healthcare provider
– Deciding whether to participate in clinical trials or experimental treatments
– Evaluating the benefits and risks of alternative therapies
– Choosing to focus on quality of life rather than aggressive treatment
– Deciding whether to engage in complementary therapies or supportive care
– Assessing the financial implications of ongoing treatment
– Deciding whether to involve family and friends in the decision-making process
– Choosing to stay positive and maintain hope despite challenges

"MyDadAndMyeloma: Hey all. I introduced myself and my dad, whose myeloma was caught very early after spending eight years in the smoldering phase, last week. You all were so helpful in calming me about the proposed treatments and gave me a lot of information to give to my parents as well as some questions to ask the oncologist.
The thing that's keeping me up at night right now is the fact that he's going to start treatment next week. I don't know the doses yet of the Darzalex, Revlimid and dexamethasone or frequency. My dad had bone marrow extracted yesterday and I believe they will solidify the treatment plan with his oncologist either tomorrow or Monday.
Regardless, he is going to start some level of treatment within the next 10 days. We have a

new immune evasive strain picking up steam here in the US, the BQ sublineages of omicron. Early data from parts of the world affected by this are that monoclonal antibody treatment post infection in otherwise healthy people is not really working. My whole family is fully up-to-date on our vaccinations and our boosters. We all received the bivalent booster within the last three weeks at varying times. My parents have both had their flu shot as well within the last two weeks.

But in trying to juxtapose another cold weather Covid surge with a new sublineage against the fact that my dad will be in his first six months of treatment as this new wave is threatening to rise here in the US has me super concerned. I feel like I need to tell my mom to not take my dad to the grocery store with her even if he is wearing a well fitting mask, or better yet, to let myself and my husband do that kind of shopping for them. likewise, it doesn't seem to me to be a very good idea for them to be dining indoors at least during the first few months, possibly the first six months, of his treatment.

I have urged my parents to bring this up with their oncologist. I will find out on Sunday if they have done so or be able to gauge if they plan to do so. My concern is that they won't because they don't want to hear news that they don't want to hear, and that my mother's posture along with my dad's is that dining out together, and sometimes with their vaccinated friends, are part of their quality of life. And I get that, I'm just talking about suspending that activity and any other risky activity until he is headed towards maintenance level treatment. I know that if they make that decision and then my dad comes down with Covid and there is a bad outcome as a result, they're not gonna remember the dinner and they're gonna wish they hadn't done it.

So what say all of you with respect to safety given we are very likely to already be in the beginnings of another Covid surge? I am sincerely trying to plan for their resistance to affectively locking themselves back down during the first six months of his treatment, although I will be relieved if I wind up being pleasantly surprised. I just need to arm myself with information from others."

## Surface Behaviors:

– Starting treatment for myeloma
– Concerns about new strain of Covid-19
– Need for information and support
– Urging parents to discuss concerns with oncologist
– Balancing quality of life with safety precautions

## Vulnerable Moments:

– Waiting for treatment plan confirmation
– Feeling anxious about potential Covid-19 exposure
– Concerns about parents' resistance to safety measures
– Fear of negative outcomes if precautions are not taken

## Choice Points:

– Deciding whether to continue dining indoors during treatment
– Choosing who does the grocery shopping
– Considering the impact of potential Covid-19 surge on safety measures
– Deciding whether to prioritize quality of life or safety during treatment journey

“RobbedByEndy: My dad (59) was just diagnosed with lgG kappa multiple myeloma from a hematologist/oncologist. We are awaiting results from bone marrow biopsy and he’s also getting bone X-rays. He is getting a blood transfusion and treatment with darzalex, revlimid, velcade, and decadron starting this Wednesday and will continue for 4 months. I will be his primary caretaker taking him to appointments and helping him manage any symptoms from this course of treatment. We meet with the nurse to discuss any questions we may have on Monday. I am scared as my dad has preexisting conditions like sleep apnea and obesity that could make this more difficult to beat. He’s also a smoker but is obviously going to need to stop that.
Could you help me interpret this blood work? This is everything the doctor highlighted. I’m sorry I’m not very educated on this and I need to learn. We expect to learn more from the bone marrow test.
Kappa Lt chain: 4670.7 mg/L
Lambda Lt  chain: 3.6 mg/L
llg (m protein): 7437 mg/dl
RBC: 2.30 (x 10*6/UL)
Hemoglobin: 8.1 g/dl
Platelets: 66 (x 10*3/UL)
Creat: 1.28 mg/dl
BUN: 28.5 mg/dl
Calcium: 10.5 mg/dl
Total protein: 11.4 g/dl
Albumin: 3.5 g/dl
Globulin: 7.9 calc
Thank you”

## Surface Behaviors:
– Blood transfusion
– Treatment with darzalex, revlimid, velcade, and decadron
– Meeting with nurse to discuss questions
– Primary caretaker role
– Managing symptoms from treatment

## Vulnerable Moments:
– Waiting for bone marrow biopsy results
– Concerns about preexisting conditions (sleep apnea, obesity)
– Fear and uncertainty about the diagnosis and treatment
– Need for education and understanding of the blood work
– Need for support and guidance in caretaker role

## Choice Points:
– Decision to start treatment with darzalex, revlimid, velcade, and decadron
– Decision to stop smoking
– Decision to actively manage symptoms and side effects
– Decision to seek further information and clarification from the nurse

– Decision to prioritize and address preexisting conditions during treatment

“amy-victor-27: I’m starting this Friday.  I’m curious to know what people’s experiences are with this.  I am taking singulair to help with transfusion reactions.”

## Surface Behaviors:
– Starting a new treatment
– Seeking information and experiences from others
– Taking Singulair for transfusion reactions

## Vulnerable Moments:
– Feeling curious and uncertain about the treatment
– Seeking support and reassurance from others
– Being open to influence and advice

## Choice Points:
– Deciding to start the treatment
– Choosing to rely on others' experiences
– Deciding to take Singulair for transfusion reactions

“Adept-Variety2162: ”

## Surface Behaviors:
– Initial symptoms
– Seeking medical advice
– Starting treatment
– Monitoring progress
– Experiencing side effects
– Adjusting treatment
– Seeking second opinion
– Engaging in self-care
– Seeking support groups

## Vulnerable Moments:
– Receiving diagnosis
– Facing treatment uncertainty
– Dealing with pain or discomfort
– Coping with emotional distress
– Experiencing treatment failure
– Managing financial burden
– Navigating healthcare system
– Dealing with caregiver stress
– Facing end-of-life decisions

## Choice Points:
– Choosing treatment options
– Deciding on surgery or alternative therapies
– Selecting healthcare providers

- Determining medication adherence
- Opting for clinical trials
- Deciding on palliative care
- Choosing to disclose diagnosis
- Deciding on treatment cessation
- Making advance care plans

“ferndudekween: In 2019, I was diagnosed with Stage 1 MM and underwent chemotherapy and an autologous stem cell transplant surgery.
I'm sad to announce that it has come back recently. I officially relapsed according to my doctor, who is giving me 2 treatment options:
1. **The Standard** \- Darzalex + Pomalyst + Dexamethasone combo
2. **Clinical Trial** \- Lefluomide + Pomalyst + Dexamethasone combo
For anyone who has undergone or is currently doing the clinical trial, what has your experience been? Thank you all for your attention and sharing your story & thoughts.”

### Surface Behaviors:
- Diagnosis of Stage 1 MM
- Undergoing chemotherapy and autologous stem cell transplant surgery
- Relapse of MM
- Treatment options presented by the doctor

### Vulnerable Moments:
- Receiving the news of relapse
- Facing the decision between standard treatment and clinical trial
- Seeking advice and experiences from others

### Choice Points:
- Choosing between the standard treatment option
- Considering participation in the clinical trial

# Surface Behaviors

| # | Behavior | Content |
|---|---|---|
| 1. | Initial symptoms of neck pain | Link to Content |
| 2. | Immediate neck surgery for bone damage | Link to Content |
| 3. | Chemotherapy treatment | Link to Content |
| 4. | Stem-cell transplant | Link to Content |
| 5. | Rising lambda count indicating relapse | Link to Content |
| 6. | Restarting treatment with revlimid and other drugs | Link to Content |
| 7. | Darzalex treatments with no improvement | Link to Content |
| 8. | Frailty and exhaustion | Link to Content |
| 9. | Hospitalization and palliative care | Link to Content |
| 10. | Diagnosis of Multiple Myeloma and AL Amyloidosis | Link to Content |
| 11. | Treatment with DVTD (daratumumab, bortezomib, thalidomide, and dexamethasone) | Link to Content |
| 12. | Remission after 6 months of treatment | Link to Content |
| 13. | Self-administration of bortezomib injections at home | Link to Content |
| 14. | Hospital visits every 4 weeks for daratumumab injection | Link to Content |
| 15. | Dialysis 3 times a week for 4.5 hours | Link to Content |
| 16. | Specialist unit in London for Amyloidosis care | Link to Content |
| 17. | Yearly tests and scans to monitor protein levels | Link to Content |
| 18. | Collection of stem cells for future transplant | Link to Content |
| 19. | Progression of disease despite treatment | Link to Content |
| 20. | Exhaustion from long-term chemotherapy | Link to Content |
| 21. | Trying different drugs to manage the condition | Link to Content |
| 22. | Rising light chains | Link to Content |
| 23. | Seeking support and encouragement | Link to Content |

| # Behavior | Content |
|---|---|
| 24. Feeling discouraged by limited treatment options | Link to Content |
| 25. Looking for alternative solutions | Link to Content |
| 26. Dealing with the physical and emotional toll of treatment | Link to Content |
| 27. Hoping for positive outcomes | Link to Content |
| 28. Starting treatment for myeloma | Link to Content |
| 29. Concerns about new strain of Covid-19 | Link to Content |
| 30. Need for information and support | Link to Content |
| 31. Urging parents to discuss concerns with oncologist | Link to Content |
| 32. Balancing quality of life with safety precautions | Link to Content |
| 33. Blood transfusion | Link to Content |
| 34. Treatment with darzalex, revlimid, velcade, and decadron | Link to Content |
| 35. Meeting with nurse to discuss questions | Link to Content |
| 36. Primary caretaker role | Link to Content |
| 37. Managing symptoms from treatment | Link to Content |
| 38. Starting a new treatment | Link to Content |
| 39. Seeking information and experiences from others | Link to Content |
| 40. Taking Singulair for transfusion reactions | Link to Content |
| 41. Initial symptoms | Link to Content |
| 42. Seeking medical advice | Link to Content |
| 43. Starting treatment | Link to Content |
| 44. Monitoring progress | Link to Content |
| 45. Experiencing side effects | Link to Content |
| 46. Adjusting treatment | Link to Content |
| 47. Seeking second opinion | Link to Content |
| 48. Engaging in self-care | Link to Content |
| 49. Seeking support groups | Link to Content |
| 50. Diagnosis of Stage 1 MM | Link to Content |

| # | Behavior | Content |
|---|---|---|
| 51. | Undergoing chemotherapy and autologous stem cell transplant surgery | Link to Content |
| 52. | Relapse of MM | Link to Content |
| 53. | Treatment options presented by the doctor | Link to Content |

# Vulnerable Moments

| # | Moment | Content |
|---|---|---|
| 1. | Receiving the initial diagnosis | Link to Content |
| 2. | Facing the need for immediate surgery | Link to Content |
| 3. | Dealing with the relapse after successful treatment | Link to Content |
| 4. | Experiencing lack of response to treatment | Link to Content |
| 5. | Being hospitalized and experiencing severe health decline | Link to Content |
| 6. | Transitioning to palliative care | Link to Content |
| 7. | The crash and decline in health | Link to Content |
| 8. | Transfer to hospice care | Link to Content |
| 9. | Final moments and passing | Link to Content |
| 10. | Receiving the diagnosis of Multiple Myeloma and AL Amyloidosis | Link to Content |
| 11. | Undergoing treatment and experiencing potential side effects | Link to Content |
| 12. | Waiting for results to determine remission status | Link to Content |
| 13. | Adjusting to self-administration of injections | Link to Content |
| 14. | Coping with the need for regular dialysis sessions | Link to Content |
| 15. | Reliance on specialized care from the London unit | Link to Content |
| 16. | Anxiety and uncertainty during yearly tests and scans | Link to Content |
| 17. | Preparing for the upcoming stem cell transplant | Link to Content |
| 18. | Managing emotional and physical well-being throughout the journey | Link to Content |
| 19. | Feeling exposed and vulnerable due to disease progression | Link to Content |
| 20. | Needing emotional support during a challenging journey | Link to Content |
| 21. | Open to advice and encouragement from others | Link to Content |
| 22. | Seeking reassurance and hope in difficult times | Link to Content |

| # | Moment | Content |
|---|---|---|
| 23. | Feeling uncertain about the future | Link to Content |
| 24. | Experiencing frustration and disappointment with treatment options | Link to Content |
| 25. | Longing for a breakthrough in treatment | Link to Content |
| 26. | Struggling with the physical and emotional side effects of chemotherapy | Link to Content |
| 27. | Desiring a pep talk to boost morale | Link to Content |
| 28. | Waiting for treatment plan confirmation | Link to Content |
| 29. | Feeling anxious about potential Covid-19 exposure | Link to Content |
| 30. | Concerns about parents' resistance to safety measures | Link to Content |
| 31. | Fear of negative outcomes if precautions are not taken | Link to Content |
| 32. | Waiting for bone marrow biopsy results | Link to Content |
| 33. | Concerns about preexisting conditions (sleep apnea, obesity) | Link to Content |
| 34. | Fear and uncertainty about the diagnosis and treatment | Link to Content |
| 35. | Need for education and understanding of the blood work | Link to Content |
| 36. | Need for support and guidance in caretaker role | Link to Content |
| 37. | Feeling curious and uncertain about the treatment | Link to Content |
| 38. | Seeking support and reassurance from others | Link to Content |
| 39. | Being open to influence and advice | Link to Content |
| 40. | Receiving diagnosis | Link to Content |
| 41. | Facing treatment uncertainty | Link to Content |
| 42. | Dealing with pain or discomfort | Link to Content |
| 43. | Coping with emotional distress | Link to Content |
| 44. | Experiencing treatment failure | Link to Content |
| 45. | Managing financial burden | Link to Content |
| 46. | Navigating healthcare system | Link to Content |
| 47. | Dealing with caregiver stress | Link to Content |
| 48. | Facing end-of-life decisions | Link to Content |

| # | Moment | Content |
|---|---|---|
| 49. | Receiving the news of relapse | Link to Content |
| 50. | Facing the decision between standard treatment and clinical trial | Link to Content |
| 51. | Seeking advice and experiences from others | Link to Content |

# Choice Points

| # | Choice | Content |
|---|---|---|
| 1. | Deciding on the course of treatment after diagnosis | Link to Content |
| 2. | Choosing to undergo surgery for bone damage | Link to Content |
| 3. | Deciding to proceed with stem-cell transplant | Link to Content |
| 4. | Determining the next steps after relapse | Link to Content |
| 5. | Choosing to try different medications, including Darzalex | Link to Content |
| 6. | Deciding to seek hospitalization and palliative care | Link to Content |
| 7. | Considering the option of hospice care | Link to Content |
| 8. | Deciding on end-of-life care measures | Link to Content |
| 9. | Making decisions regarding communication and support | Link to Content |
| 10. | Deciding on the appropriate treatment plan | Link to Content |
| 11. | Choosing to learn and administer self-injections at home | Link to Content |
| 12. | Selecting the frequency and timing of hospital visits | Link to Content |
| 13. | Opting for dialysis as a treatment option for kidney involvement | Link to Content |
| 14. | Deciding to seek care from the specialist unit in London | Link to Content |
| 15. | Determining the frequency and extent of follow-up tests and scans | Link to Content |
| 16. | Electing to undergo stem cell transplant after achieving remission | Link to Content |
| 17. | Making choices to prioritize self-care and emotional support | Link to Content |
| 18. | Deciding on the level of engagement with online resources and information | Link to Content |
| 19. | Deciding whether to continue with the current treatment or explore other options | Link to Content |
| 20. | Choosing to seek a second opinion from a different healthcare provider | Link to Content |
| 21. | Deciding whether to participate in clinical trials or experimental treatments | Link to Content |

| # | Choice | Content |
|---|---|---|
| 22. | Evaluating the benefits and risks of alternative therapies | Link to Content |
| 23. | Choosing to focus on quality of life rather than aggressive treatment | Link to Content |
| 24. | Deciding whether to engage in complementary therapies or supportive care | Link to Content |
| 25. | Assessing the financial implications of ongoing treatment | Link to Content |
| 26. | Deciding whether to involve family and friends in the decision-making process | Link to Content |
| 27. | Choosing to stay positive and maintain hope despite challenges | Link to Content |
| 28. | Deciding whether to continue dining indoors during treatment | Link to Content |
| 29. | Choosing who does the grocery shopping | Link to Content |
| 30. | Considering the impact of potential Covid-19 surge on safety measures | Link to Content |
| 31. | Deciding whether to prioritize quality of life or safety during treatment journey | Link to Content |
| 32. | Decision to start treatment with darzalex, revlimid, velcade, and decadron | Link to Content |
| 33. | Decision to stop smoking | Link to Content |
| 34. | Decision to actively manage symptoms and side effects | Link to Content |
| 35. | Decision to seek further information and clarification from the nurse | Link to Content |
| 36. | Decision to prioritize and address preexisting conditions during treatment | Link to Content |
| 37. | Deciding to start the treatment | Link to Content |
| 38. | Choosing to rely on others' experiences | Link to Content |
| 39. | Deciding to take Singulair for transfusion reactions | Link to Content |
| 40. | Choosing treatment options | Link to Content |
| 41. | Deciding on surgery or alternative therapies | Link to Content |
| 42. | Selecting healthcare providers | Link to Content |
| 43. | Determining medication adherence | Link to Content |
| 44. | Opting for clinical trials | Link to Content |

| # Choice | Content |
|---|---|
| 45. Deciding on palliative care | Link to Content |
| 46. Choosing to disclose diagnosis | Link to Content |
| 47. Deciding on treatment cessation | Link to Content |
| 48. Making advance care plans | Link to Content |
| 49. Choosing between the standard treatment option | Link to Content |
| 50. Considering participation in the clinical trial | Link to Content |

# Sentiment Analysis of Patient Transcripts

## Categories

| Hierarchy | Score |
|---|---|
| Medical Health > Diseases And Conditions > Blood Disorders | 90.06% |
| Medical Health > Diseases And Conditions > Endocrine And Metabolic Diseases > Thyroid Disorders | 87.81% |
| Medical Health > Vaccines | 78.32% |

## Sentiment

| | |
|---|---|
| **Negative** | -40.39% |

## Emotions

| | |
|---|---|
| **Anger** | 05.69% |
| **Disgust** | 04.17% |
| **Fear** | 12.71% |
| **Joy** | 27.59% |
| **Sadness** | 36.83% |

## Keywords

| Text | Count | Relevance | Emotions | | | | |
|---|---|---|---|---|---|---|---|
| | | | Anger | Disgust | Fear | Joy | Sadness |
| dad's primary companion | 1 | 64.44% | 01.88% | 01.21% | 10.56% | 17.88% | 47.69% |
| successful treatment | 1 | 62.41% | 01.12% | 01.61% | 15.19% | 12.46% | 46.74% |
| first Darzalex treatment | 1 | 56.36% | 01.68% | 20.47% | 02.59% | 07.37% | 70.71% |
| dad's story | 1 | 56.36% | 01.88% | 01.21% | 10.56% | 17.88% | 47.69% |
| lot of literature | 1 | 54.35% | 01.12% | 01.61% | 15.19% | 12.46% | 46.74% |
| middle of the night | 1 | 54.13% | 02.94% | 01.78% | 20.23% | 04.65% | 50.29% |
| initial diagnosis | 1 | 54.12% | 01.12% | 01.61% | 15.19% | 12.46% | 46.74% |
| extensive bone lesions | 1 | 53.81% | 02.53% | 00.71% | 07.64% | 02.22% | 84.61% |
| cold weather Covid surge | 1 | 53.67% | 03.60% | 02.12% | 33.37% | 03.02% | 16.34% |
| new immune evasive strain | 1 | 53.57% | 39.18% | 02.81% | 23.41% | 01.94% | 10.73% |
| initial symptoms | 1 | 53.56% | 02.53% | 00.71% | 07.64% | 02.22% | 84.61% |
| host of other drugs | 1 | 53.54% | 04.14% | 05.39% | 10.13% | 09.62% | 40.41% |
| pulse ox | 1 | 53.44% | 02.94% | 01.78% | 20.23% | 04.65% | 50.29% |

| Text | Count | Relevance | Emotions | | | | |
|---|---|---|---|---|---|---|---|
| | | | Anger | Disgust | Fear | Joy | Sadness |
| good days | 1 | 53.30% | 00.20% | 00.10% | 01.44% | 53.33% | 67.89% |
| doctor's visits | 1 | 53.09% | 01.88% | 01.21% | 10.56% | 17.88% | 47.69% |
| little bit | 1 | 53.08% | 00.99% | 00.89% | 14.00% | 08.00% | 76.45% |
| Early data | 1 | 52.98% | 01.21% | 03.55% | 04.63% | 18.56% | 23.97% |
| further Darzalex treatments | 1 | 52.94% | 07.76% | 01.77% | 02.12% | 37.61% | 27.80% |
| bone marrow | 1 | 52.79% | 04.10% | 02.33% | 13.72% | 19.46% | 26.05% |
| palliative care | 2 | 52.58% | 01.08% | 01.84% | 04.49% | 34.12% | 58.32% |
| blood transfusion | 2 | 52.50% | 05.16% | 02.58% | 11.30% | 27.90% | 26.72% |
| Clinical Trial | 2 | 52.32% | 02.32% | 01.01% | 05.42% | 22.06% | 62.97% |
| lambda count | 2 | 52.26% | 05.72% | 01.36% | 04.64% | 27.06% | 16.72% |
| treatment plan | 1 | 52.21% | 04.77% | 00.53% | 11.30% | 20.02% | 23.64% |
| grocery store | 1 | 52.18% | 02.79% | 00.74% | 05.70% | 54.26% | 14.46% |
| amy-victor-27 | 1 | 52.15% | 00.90% | 01.17% | 05.81% | 35.38% | 49.51% |
| Multiple Myeloma | 1 | 52.13% | 02.39% | 04.50% | 06.95% | 04.93% | 61.32% |
| exact cocktail of drugs | 1 | 52.11% | 03.09% | 41.99% | 15.19% | 09.43% | 12.72% |
| sleep apnea | 1 | 52.05% | 01.04% | 00.69% | 65.81% | 01.24% | 66.21% |
| primary caretaker | 1 | 52.02% | 02.11% | 00.96% | 16.39% | 05.81% | 57.40% |
| cardiac enzymes | 1 | 51.99% | 04.02% | 01.21% | 18.53% | 05.45% | 63.50% |
| parts of the world | 1 | 51.78% | 01.21% | 03.55% | 04.63% | 18.56% | 23.97% |
| lot of information | 1 | 51.75% | 08.36% | 00.29% | 01.47% | 61.97% | 51.74% |
| mother’s posture | 1 | 51.75% | 02.26% | 02.17% | 12.17% | 56.42% | 21.49% |
| blood counts | 2 | 51.69% | 06.53% | 03.86% | 10.36% | 21.83% | 28.49% |
| neck pain | 1 | 51.69% | 02.53% | 00.71% | 07.64% | 02.22% | 84.61% |
| Darzelex treatments | 1 | 51.60% | 00.87% | 02.41% | 05.04% | 05.50% | 74.55% |
| new sublineage | 1 | 51.50% | 03.60% | 02.12% | 33.37% | 03.02% | 16.34% |
| bad outcome | 1 | 51.48% | 02.61% | 06.02% | 04.89% | 13.30% | 25.02% |
| AL Amyloidosis | 2 | 51.35% | 01.69% | 05.09% | 07.75% | 13.45% | 58.70% |
| very good idea | 1 | 51.26% | 04.02% | 01.73% | 09.15% | 65.74% | 15.82% |
| treatment | 6 | 51.23% | 05.02% | 04.18% | 11.58% | 25.92% | 34.05% |
| specialist unit | 1 | 51.22% | 01.32% | 02.33% | 08.33% | 26.94% | 51.09% |
| wonderful night | 1 | 51.22% | 00.82% | 00.27% | 05.16% | 47.42% | 29.80% |
| months of treatment | 2 | 51.18% | 03.13% | 02.41% | 19.44% | 31.92% | 16.57% |
| hospice care | 1 | 51.11% | 01.50% | 01.54% | 15.46% | 12.66% | 27.94% |
| relapse rate | 1 | 51.10% | 01.12% | 01.61% | 15.19% | 12.46% | 46.74% |
| bone damage | 1 | 51.06% | 02.53% | 00.71% | 07.64% | 02.22% | 84.61% |
| proposed treatments | 1 | 51.06% | 08.36% | 00.29% | 01.47% | 61.97% | 51.74% |
| pep talk | 1 | 51.05% | 05.91% | 01.13% | 25.95% | 34.48% | 09.58% |