

A scenic view of Whitehorse, Yukon, featuring a river, a town, and mountains in the background. The text "Good Morning Everyone!" is overlaid in blue script at the top.

Good Morning Everyone!

MICHAEL GLADISH

Whitehorse, Yukon

*Survey – Research Priorities Patients on
Dialysis*

PATIENT ROLE IN RESEARCH



Involving patients as active participants:


- New and evolving process
- Facilitates dialogue between patients and researchers
- Exchange of ideas and approaches
- Strengthens patient confidence in the outcome of the research



Traditionally patients have played passive role in research.

Survey demonstrates patients offer:

- Practical and experiential knowledge to complement research
- Unique insight and experiences that can guide the development and implementation of research

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- Criticism of proposed research or treatment
 - Ideas and approaches that may not otherwise be considered

PATIENT EXPECTATIONS



- Share the same goals with researchers and health care providers for satisfactory treatment outcome and a high quality of life
- Expectations and perceptions of how to achieve those goals may well be different than care providers
- Affected by number of diverse factors

SURVEY



- Paper - Views of Canadian patients on or nearing dialysis and their caregivers: a thematic analysis
- Focus on patient concerns not included in the top ten research questions - issues of importance to patients
- Analysis of patient and caregiver issues and concerns

FOUR THEMES



- Gaining knowledge
- Maintaining quality of life
- Sustaining psychosocial well-being
- Ensuring appropriate care

PATIENT PRIORITY



Theme most important to patients

QUALITY OF LIFE

WHO DEFINITIONS




Quality of Life:

“an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.”

Health:

“A state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.”



WHO Quality of Life and Health
definitions must be considered together.

QUALITY OF LIFE



Measure is subjective and influenced by:

- Changing expectations
- Longevity and severity of disease
- Symptoms and side effects
- Changes to family, social and economic circumstances

FACTORS AFFECTING QUALITY OF LIFE



In order of importance:

- Gaining knowledge
- Appropriate care
- Psychosocial well-being

GAINING KNOWLEDGE



- Information and knowledge empowers patients
- Affords greater sense of control of one's life

APPROPRIATE CARE



Mechanisms, protocols and standards that ensure quality treatment and the management of the physical aspects of symptoms and side affects.

When Care and treatment is at it's best, we are at our best.

PSYCHOSOCIAL WELL BEING



Aspects such as:

- Bodily image and self esteem
- State of mind
- Social relationships and support
- Environment and economic circumstances

CHANGE



A change to any of three factors changes our:

- Expectations and response to our condition
- Perception of our Quality of Life

KD PRESENTS CHALLENGES

- Everyday normal living activities
- Travel, family and social activities

A desire to achieve a “normal life”



ACHIEVING GOOD QUALITY OF LIFE

A decorative graphic consisting of a horizontal bar with a color gradient from dark blue on the left to bright yellow on the right. To the right of the bar is a large, stylized arrow pointing to the right, filled with a gradient from dark brown to light brown.

- Appropriate Information about KD
- At right time – stage
- Right amount and form

Enables patients ability to adapt to KD and
reduces stress and anxiety

HOW WE FEEL



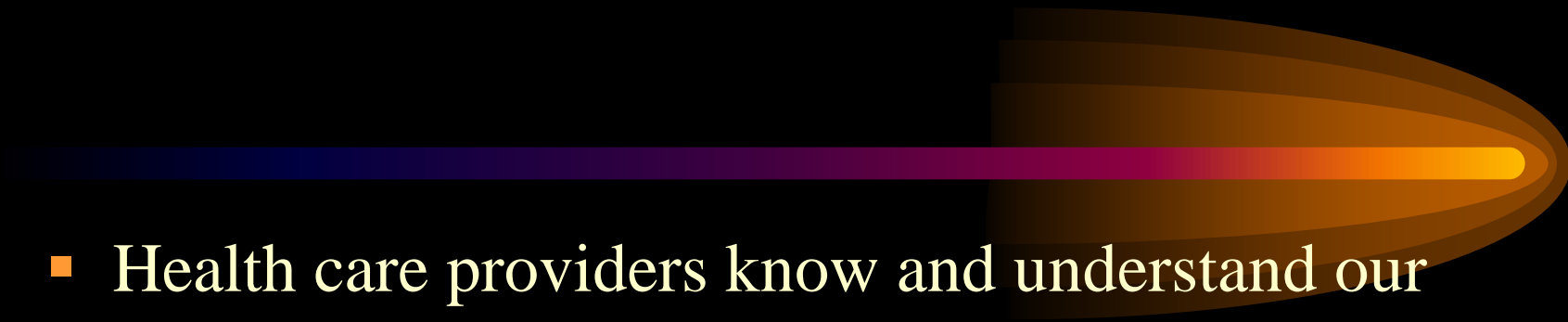
OUR NEEDS

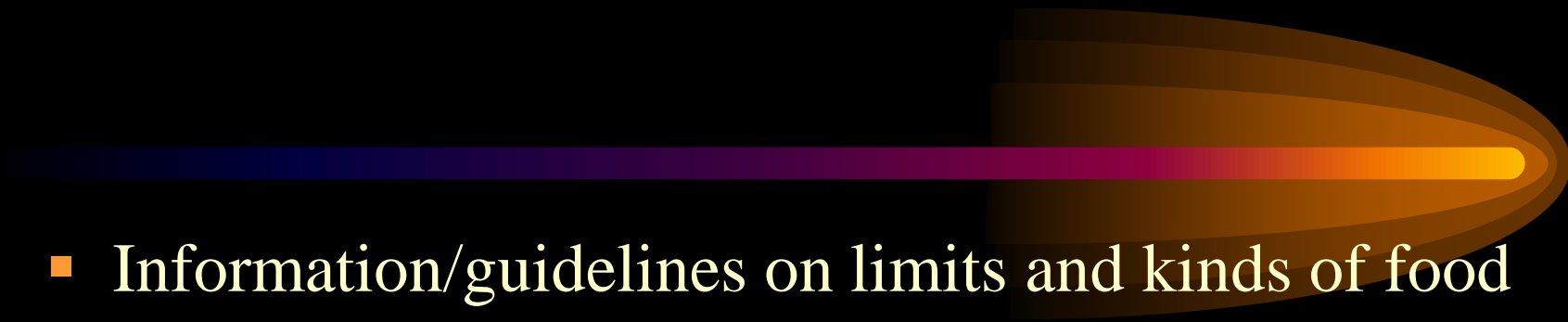
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- Clear, continuing communication in a language we comprehend
- Treatment options
- Mechanism and protocols of treatment specific to individual needs
- Opinions, desires and needs are considered



*We are the most important member
of the team.*

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- Health care providers know and understand our personal, social and environmental circumstances
 - Available sources and resources for information about KD
 - Must feel part of the treatment solution and that our opinions, desires and needs are considered

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- Information/guidelines on limits and kinds of food we can eat
 - Reduce the barriers to travel
 - Improve availability of services

APPROPRIATE CARE

- Mechanisms, protocols and standards for the delivery of our care and treatment
- Management of the physical and psychological effects of symptoms and side effects



Hildal Remember to *unhook* the patients before discarding the tubing.

FACTORS AFFECTING CARE



- Care and treatment can either reinforce or undermine perceptions of quality of life
- Level and quality of resources and services available regionally / nationally
- Geography can impact the delivery of our treatment



Don't worry, I'll find a good site soon.

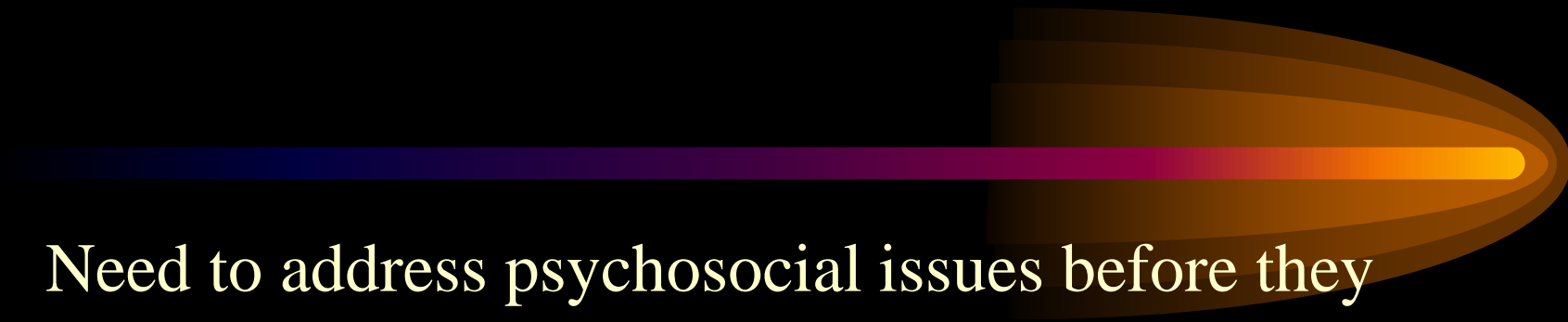


PSYCHOSOCIAL IMPACT



Long years with burden of disease creates:

- Mental and emotional toll on patients and families
- Loss of intimacy
- Break down in family relations / social connections
- Depression and psychological side effects



Need to address psychosocial issues before they
undermine quality of life.

*Our physical well being contributes to our
psychological well being and vice versa.*

IMPROVEMENT STRATEGIES



- Create / improve standards for quality and dissemination of information / knowledge
- Review / develop appropriate and comprehensive mechanisms/protocols for treatment
- Understand how treatment, personal and environmental factors affect quality of life
- Ensure appropriate resources for physical and psychological treatment

IMPORTANCE OF PATIENT ENGAGEMENT



We are the one's living the disease.

CONCLUSION



- Take the initiative to become more engaged in decisions about treatment
- Clearly and emphatically communicate concerns, desires and needs
- Become active participants to help design - critique research
- Participate in conferences – BC Kidney Days



THANK YOU