



**Educating Patients, Families
and Caregivers about
Skin Changes At Life's End
(SCALE)**

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Disclosures

- Advisory Board–WoundSource; Medline Skin Health
- Receives financial compensation for expert witness work
- Co-Chair, Skin Changes At Life's End (SCALE) Panel
- Author, Skin Changes At Life's End (SCALE) Guide for Patients, Families and Caregivers (WoundSource White Paper 2021)



Photos courtesy of
Dr. Diane L. Krasner
unless noted otherwise



Objectives



1. To describe the Skin Changes At Life's End (SCALE) consensus document
2. To appreciate reasons for educating patients, families and caregivers about SCALE wounds
3. To identify effective strategies for educating patients, families and caregivers about SCALE wounds





Part 1

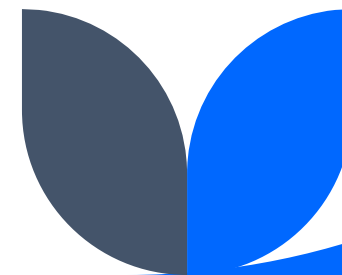
**Brief Overview of
Skin Changes At Life's
End (SCALE)**

Part 2

**Why Educate Patients,
Families and Caregivers
about SCALE?**

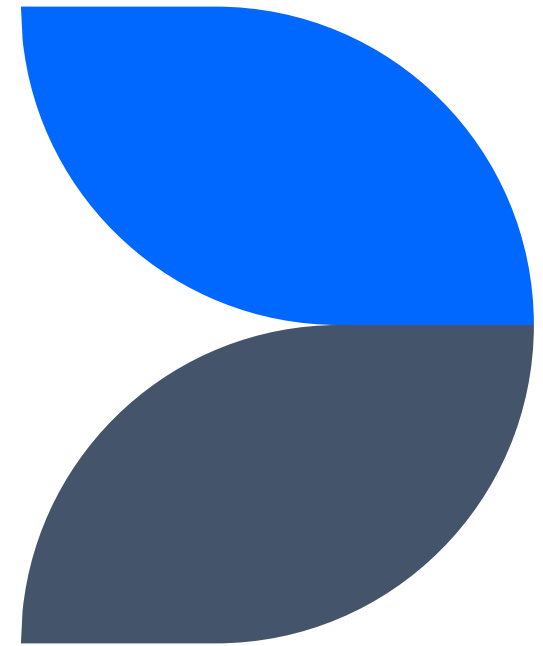
Part 3

**Strategies for Teaching
SCALE**



Part 1

Brief Overview of
Skin Changes At Life's
End (SCALE)



Do you use an end-of-life/palliative wound care guideline/pathway in your facility/practice?

1. YES

2. NO



Skin Changes At Life's End (SCALE)

**SCALE Final Consensus Statement,
October 1, 2009**

Go to CWCE 2018 e-Book to read
or my website to download: www.dianelkrasner.com

Scale Expert Panel. SCALE: skin changes at life's end. In Krasner DL, van Rijswijk L, eds. *Chronic Wound Care: The Essentials e-Book*. HMP; 2018:303-317. <https://fliphtml5.com/zxoes/kzzg/basic>



2008 Creation of an International Expert Panel

Dr. Thomas Stewart, co-founder of the NPUAP (now the NPIAP), convened an international expert panel April 4-6, 2008, in Chicago, IL, to explore issues surrounding skin changes and wounds that people experience when they are dying.

The panel included physicians, nurses, legal experts, researchers, caregivers, and a medical writer. All panel members had extensive experience with the subject matter.

The panel drafted 10 statements and decided to use a modified Delphi Process to reach consensus and then develop a consensus document on the subject.

Sibbald R.G., et al. *Adv Skin Wound Care*. 2010; 23: 225-236.

A Range of Skin Changes & Wounds in Dying Patients: From Mottling to Fungating Wounds (Not Just Pressure Injuries)



Sibbald R.G., et al. *Adv Skin Wound Care*. 2010; 23:
225-236.

3/19/2022

**Educating Patients, Families and Caregivers about
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Skin Changes At Life's End (SCALE)

18-month process

18 panel members

52 distinguished reviewers

Modified Delphi Process



Sibbald R.G., et al. *Adv Skin Wound Care*. 2010; 23: 225-236.

**Educating Patients, Families and Caregivers about
Skin Changes At Life's End (SCALE)**

SCALE Documents
Downloadable at www.dianelkrasner.com

Skin Changes At Life's End (SCALE)

- Final Consensus Statement
- Annotated Reference List
- Presentations
- Articles



SCALE Statement 1

Physiological changes that occur as a result of the dying process (days to weeks) may affect the skin and soft tissues and may manifest as observable (objective) changes in skin color, turgor, or integrity, or as subjective symptoms such as localized pain. These changes can be unavoidable and may occur with the application of appropriate interventions that meet or exceed the standard of care.



The VCU Pressure Ulcer Summit: The Search for Clearer Understanding and More Precise Clinical Definition of the Unavoidable Pressure Injury.

Decubitus Ominosis
Kennedy Terminal Ulcer
Skin Failure (Acute, Chronic, End Stage)
SCALE Wounds
Trombley-Brennan Terminal Tissue Injury

Alvarez OM, et al. *J Wound Ostomy Continence Nurs.* 2016;43:455-463.

NPIAP Special Events

**Unavoidable Skin Changes at the End
of Life –
Are they really pressure injuries?**

**Friday, November 19, 2021 &
Saturday, November 20, 2021
Washington, DC & Virtual**

More information at www.npiap.com

So, Where are We Today?

For every complex problem,
there is an answer that is
clear, simple, and wrong.

- H. L. Mencken



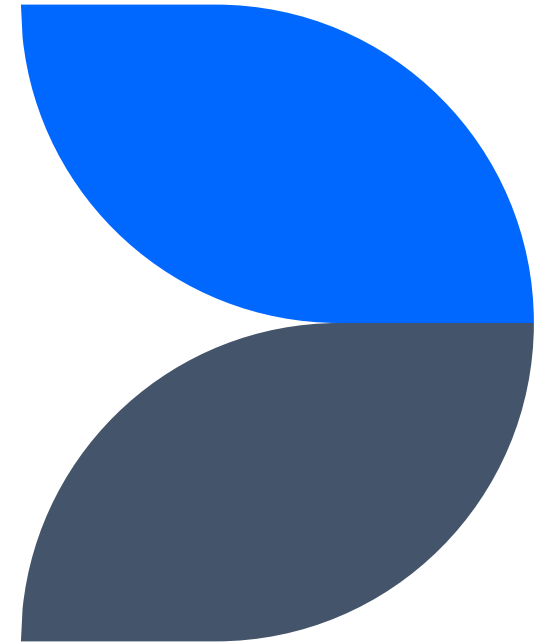
A Final Thought

Goals of care, plans of care, interventions, outcomes & documentation **MUST** address end-of-life **wounds** (or *whatever you choose to call them*)



Part 2

Why Educate Patients,
Families and Caregivers
about SCALE?



Do you use any patient, family or caregiver educational materials about end-of-life/palliative wound care in your facility/practice?

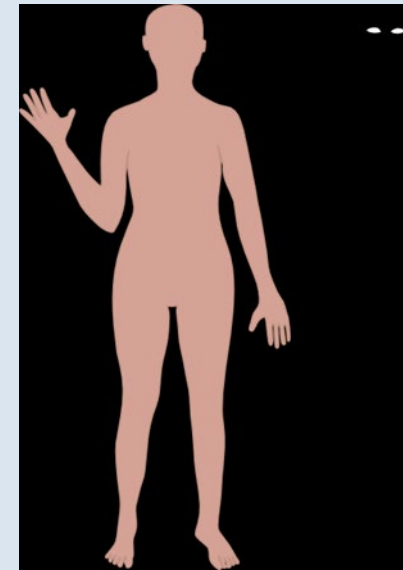
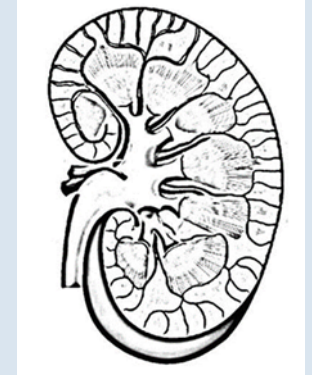
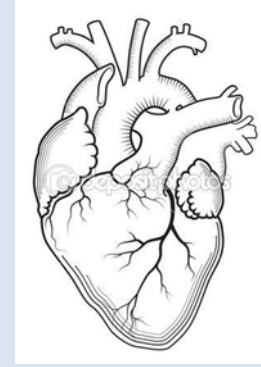
1.YES

2.NO



Unlike other end-of-life conditions –
such as heart failure and renal
(kidney) failure –
skin failure is very visible.

Teach patients, families and
caregivers:
**The skin is the body's largest organ;
it can fail, too.**



Alerting patients, families and caregivers about SCALE wounds is:



- Proactive
- No unpleasant “surprises”

Educating Patients, Families and Caregivers about
Skin Changes At Life's End (SCALE)

Alerting Patients, Families and Caregivers about SCALE Wounds

- May help to minimize family and/or caregiver *burden and guilt*
- May prevent patient, family and/or caregiver *anger*

Glajchen M. Family Caregivers in Palliative Care and Hospice: Minimizing Burden and Maximizing Support. National Hospice and Palliative Care Organization. Palliative Care Resource Series. 2016.

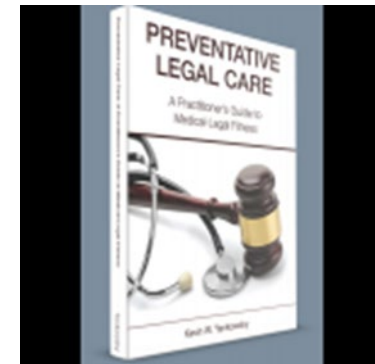
Alerting Patients, Families and Caregivers about SCALE Wounds is:

Good “preventive legal care”



We spend so much time on pressure ulcer prevention; we need to spend some time on *preventive legal care*, too!

Yankowsky K. Preventive Legal Care: A Practitioner’s Guide to Medical-Legal Fitness. Best Publishing Company, 2015.



**Educating Patients, Families and Caregivers about
Skin Changes At Life's End (SCALE)**

US Pressure Injury Lawsuits are Prevalent and Expensive

17,000

More than 17,000 lawsuits are related to pressure injuries annually*

\$251,000

Average claim cost of a US pressure injury claim is \$251,000[†]

\$\$\$Millions Tens of millions of dollars



* Berlowitz D, et al. Preventing Pressure Ulcers in Hospitals: A Toolkit for Improving Quality of Care. Agency for Healthcare Research and Quality. Available: <https://www.ahrq.gov/sites/default/files/publications/files/putoolkit.pdf>. Content last reviewed October 2014. Accessed February 18, 2019. [†] 2018 Aon General and Professional Liability Benchmark for Long Term Care Providers: Actuarial Analysis. Aon; October 2018. Content last reviewed October 2018. Accessed February 18, 2019. https://www.allianceinsgrp.com/images/uploads/knowledge_center/2018_Aon_General_and_Professional_Liability_Benchmark_for_Long_Term_Care_Providers_without_password.pdf

Communicate with Patients and Family

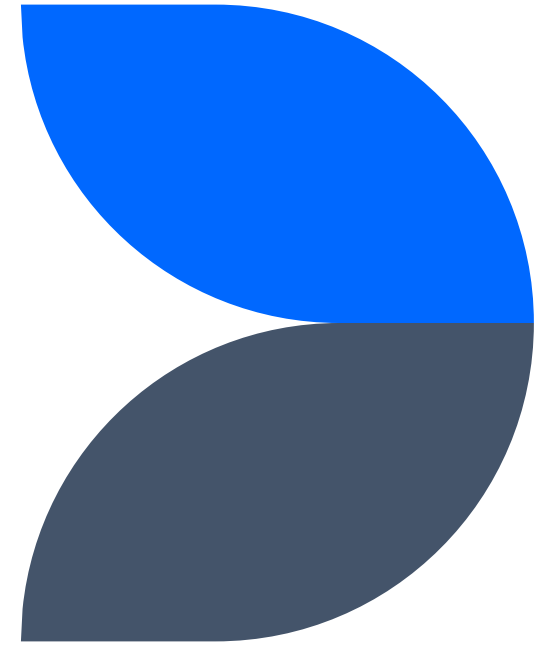
Lawsuits do not happen completely at random – they are commonly associated with problems with provider-patient communications (rather than clinical outcomes).*

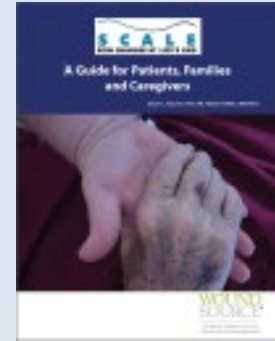
- **Educate patients, family and caregivers** about pressure ulcers and importance of prevention
- Regularly **demonstrate that prevention measures are** in place
- Clearly portray adjustments to care plans and **stress the importance of adherence**
- **Consistently and frequently communicate the** care plan goals with patients, family and caregivers and document the details of the communication

Fullam FA. The Link Between Patient Satisfaction and Malpractice Risk. Press Ganey White Paper; 2010.

Part 3

Strategies for
Teaching SCALE





SCALE: A Guide for Patients, Families & Caregivers

WoundSource White Paper 2021

Go to WoundSource White Papers

Krasner DL. Skin Changes at Life's End: A Guide for Patients, Families and Caregivers. WoundSource & Kestrel Health Information; 2021. <https://pages.woundsource.com/skin-changes-lifes-end-guide-patients-families-caregivers/>

Educating Patients, Families and Caregivers about
Skin Changes At Life's End (SCALE)

SCALE Guide 2021



- Introduction
- Types of SCALE Wounds
- Goals of Care for SCALE Wounds
- Common Treatments for SCALE Wounds
- Addressing Other Issues
- Interprofessional Team Resources for People with SCALE Wounds
- Conclusion
- References and Other Resources

SCALE Guide 2021

13 pages

Photos:

- Mottling
- Pressure Ulcers/Injuries (Bedsore)
- IAD/MASD
- Malignant (Cancer) Wounds

Callout Boxes

Examples

IAD, incontinence-associated dermatitis; MASD, moisture-associated skin damage

Krasner DL. *Skin Changes at Life's End: A Guide for Patients, Families and Caregivers*. WoundSource & Kestrel Health Information; 2021.



Written Educational Materials:



Help to improve communication

Bearden J. Wound Care Advisor. 2014;3(4):10-11, 19. http://woundcareadvisor.com/wp-content/uploads/2014/07/BP_Education_J-A14.pdf. Cioroiu M, Levine JM. *Today's Wound Clinic*. 2013;7(3):1-8.

**Educating Patients, Families and Caregivers about
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Written Educational Materials:



Ensure that care is transmitted accurately
with transitions of care

Erwin-Toth P. Offering support and resources for family caregivers [blog post]. *WoundSource*. October 30, 2014. <https://www.woundsource.com/blog/offering-support-and-resources-family-caregivers/>. Kirkland-Kyhn H, et al. *Am J Nurs*. 2018;118(3):63-67.

**Educating Patients, Families and Caregivers about
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Written Educational Materials:



Reduce patient, family and caregiver stress & anxiety

National Academies of Sciences, Engineering, and Medicine. *Families Caring for an Aging America*. The National Academies Press; 2016.

**Educating Patients, Families and Caregivers about
Skin Changes At Life's End (SCALE)**

Delivering Bad News

- **Especially important for Providers**
- **Support staff should reinforce the same message**
- **Numerous approaches & resources**
- **Train your staff**
- **Role play**



Recommended Read #1

How to Break Bad News:

A Guide for Health Care Professionals

First Edition

Robert Buckman, MD &

Yvonne Kason, MD

The Johns Hopkins University Press, 1992



Recommended Read #2

Difficult Conversations:

How to Discuss What Matters Most

Douglas Stone, Bruce Patton & Sheila Heen
of the Harvard Negotiation Project

Penguin Books, 2010



SCALE Care Pathways & Care Planning

Palliative Wound Care – Usual

**Maintenance Wound Care –
Sometimes**

Aggressive Wound Care – Rarely

End Note

To cure – occasionally

To relieve – often.

To comfort – always.

- Hippocrates



Thank you



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